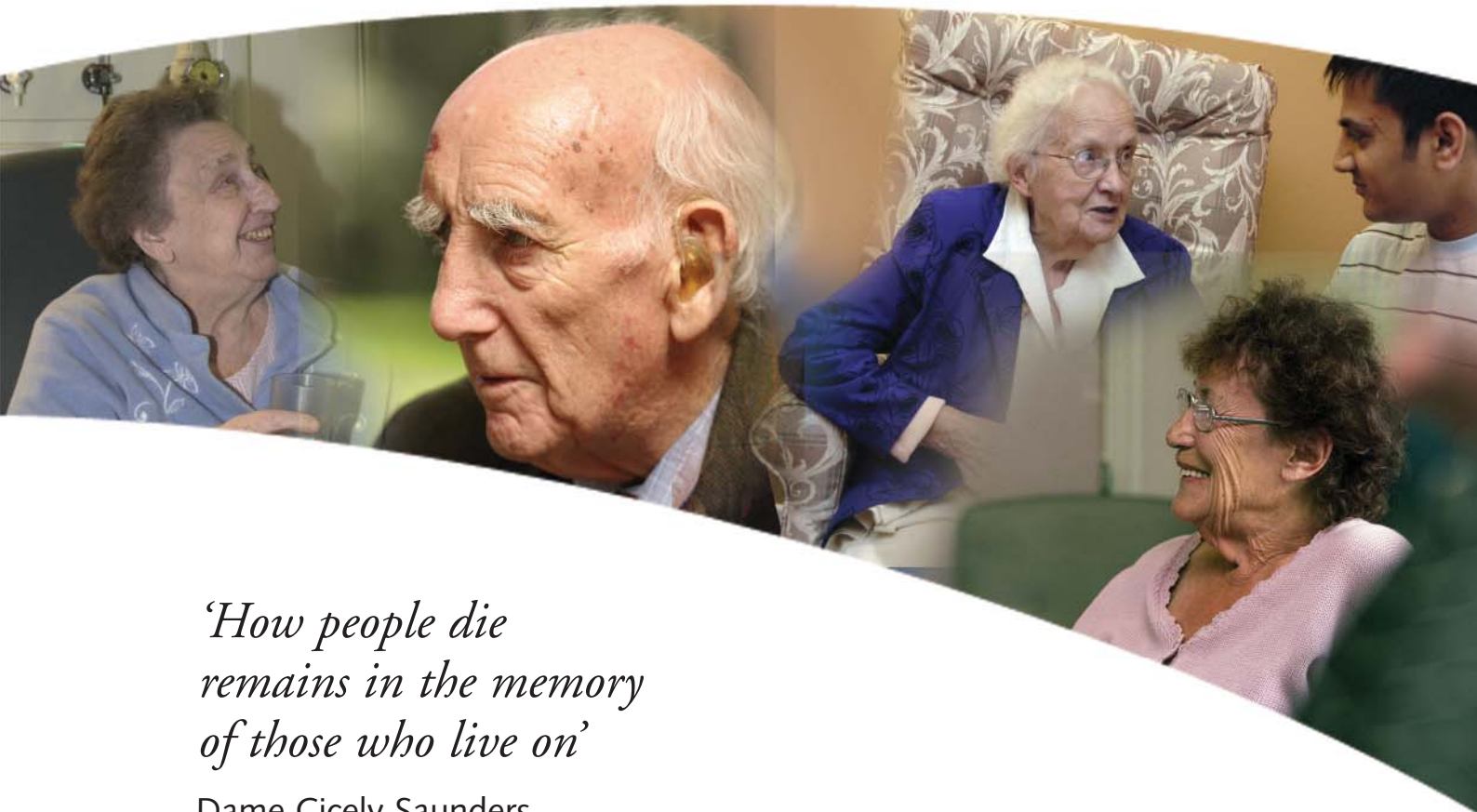


# End of Life Care Strategy

*Promoting high quality care for all adults at the end of life*



*'How people die  
remains in the memory  
of those who live on'*

Dame Cicely Saunders

Founder of the Modern Hospice Movement

July 2008

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at the end of life*

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who live on'***

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*July 2008*

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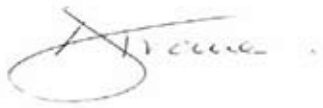
# Introduction

## **The Next Stage Review – End of Life Care Clinical Pathway Chairs for the 10 Strategic Health Authorities**


We warmly welcome the emphasis on end of life care as one of the eight clinical pathways developed by each of the Strategic Health Authorities in England as part of the Next Stage Review (NSR). As End of Life Clinical Leads, we were fortunate that our work could be informed by the emerging findings from consultation on this national End of Life Care Strategy, which had already started before the NSR process commenced.

We were able to develop and refine these emerging findings further by engaging with a large number of health and social care professionals, patients, carers and the public in each of our regions. We also welcomed the opportunity to share ideas with each other and to contribute to the further development of the national strategy.

In all ten SHAs the concept of an end of life care pathway was endorsed as a foundation for our clinical visions. This national strategy has our full support. We believe it will help us to drive forward our visions at a local level and achieve our goal of providing high quality end of life care for patients and their families.



Dr Dee Traue  
MSc MB BS MRCP  
Chair – NHS East of England End of Life  
Clinical Pathway Group  
Macmillan Consultant in Palliative  
Medicine, Cambridge University Hospitals  
NHS Foundation Trust



Dr Robin Graham-Brown  
BSc MB FRCP FRCPCH  
Chair – NHS East Midlands End of Life  
Clinical Pathway Group  
Director of Services for Older People,  
University Hospitals of Leicester NHS  
Trust



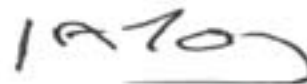
Professor Edwin Pugh  
FRCP (Edin)  
Chair – NHS North East End of Life  
Clinical Pathway Group  
Consultant in Palliative Medicine, North  
Tees and Hartlepool NHS Foundation  
Trust and Professor in Palliative Care,  
University of Teeside



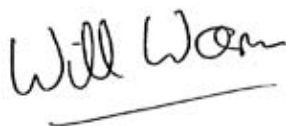
Dr David Levy  
FRCR FRCP  
Co-Chair – NHS Yorkshire and the  
Humber End of Life Clinical Pathway  
Group  
Consultant Oncologist, Sheffield  
Teaching Hospitals NHS Foundation Trust



Dr Mark Roland  
MA MB ChB FRCP  
Chair – NHS South Central End of Life  
Clinical Pathway Group  
Consultant in Respiratory Medicine,  
Portsmouth Hospitals NHS Trust



Mrs June Toovey  
RGN, MA  
Co-Chair – NHS Yorkshire and the  
Humber End of Life Clinical Pathway  
Group  
Nurse Director, Yorkshire Cancer  
Network

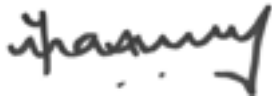


Dr Will Warin  
MB ChB MRCP  
Chair – NHS South West End of Life  
Clinical Pathway Group  
Professional Executive Committee Chair,  
Bristol Teaching Primary Care Trust

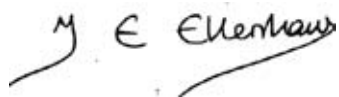


Dr Ian Douglas  
MRCP  
Chair – NHS West Midlands End of Life  
Clinical Pathway Group  
Consultant in Palliative Medicine and

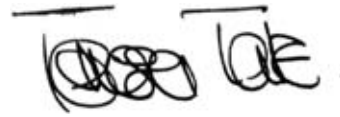
Clinical Director of Palliative Care  
Services, Worcestershire PCT



Dr John Omany  
MSc MB ChB DMRT DipPallMED  
Chair – NHS South East Coast End of Life  
Clinical Pathway Group  
Consultant in Palliative Medicine, Royal  
Surrey County Hospital and  
Medical Director and Consultant in  
Palliative Medicine,  
Woking Hospice and Surrey PCT



Professor John Ellershaw  
MA FRCP  
Chair – NHS North West End of Life  
Clinical Pathway Group  
Professor of Palliative Medicine, Royal  
Liverpool & Broadgreen University  
Hospitals NHS Trust and Marie Curie  
Hospice Liverpool and Director,  
Marie Curie Palliative Care Institute,  
University of Liverpool



Dr Teresa Tate  
FRCP FRCR  
Joint Clinical Lead – NHS London  
Framework for Action: End of Life Care  
implementation  
Medical Adviser, Marie Curie Cancer  
Care and Consultant in Palliative  
Medicine, Barts and the London NHS  
Trust



Dr Rob George  
MA MD FRCP  
Joint Clinical Lead – NHS London  
Framework for Action: End of Life Care  
implementation  
Consultant in Palliative Medicine,  
Meadow House Hospice and Senior  
Lecturer Biomedical Ethics, UCL Medical  
School





# Foreword

## by the Secretary of State for Health



This strategy, published just after the 60th birthday of the NHS, represents an important milestone for health and social care. It is the first comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life.

Each year around 500,000 people die in England. We know that although some people receive excellent care at the end of life, many do not. One of the fundamental problems is that services are not always joined up and as a result communication between staff and agencies can break down. From surveys of the general public we know that, given the opportunity and right support, most people would prefer to die at home. In practice, only a minority manage to do so. Many people die in an acute hospital, which is not their preferred place of care.

However, we also know that many people receive excellent care as their life draws to a close. Over the past forty years hospices and specialist palliative care services have demonstrated what can be done to provide physical, psychological, social and spiritual care for people and their families. In recent years new models of care have been developed by the NHS and by the voluntary sector to bring good care to a wider number of patients.

This strategy builds on the vision and expertise of hundreds of people and organisations from all walks of life. Initial work on addressing the challenges of providing high quality end of life care had commenced before the Next Stage Review got underway. This early work was given further shape and strengthened through the participation of the many clinicians who contributed to the development of the Strategic Health Authorities' visions for end of life care. This national strategy can genuinely be said to have been developed from the bottom up.

This strategy provides a framework on which local health and social care services can build. It also sets out a commitment from the government to enhance funding for end of life services. As a result of this we can be confident that the quality of end of life care, which matters to us all, will improve year on year.

A handwritten signature in black ink that reads "Alan Johnson". The signature is written in a cursive style with a large, sweeping flourish over the name.

The Rt Hon Alan Johnson MP  
Secretary of State for Health



# Executive Summary

## Background

1. Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere.
2. The demographics of death in relation to age profile, cause of death and place of death have changed radically over the course of the past century. Around 1900 most people died in their own homes. At that time acute infections were a much more common cause of death and a far higher proportion of all deaths occurred in childhood or early adult life.
3. With these changes, familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body, except on television. As a society we do not discuss death and dying openly.
4. Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve:
  - Being treated as an individual, with dignity and respect;
  - Being without pain and other symptoms;
  - Being in familiar surroundings; and
  - Being in the company of close family and/or friends.
5. Some people do indeed die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices, care homes and in their own homes. But the reality is that many do not. Many people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.

6. How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.
7. In the past, the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. Implementation of this strategy will make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

## Context

8. The themes set out in the strategy have built on the best available research evidence and on existing experience from:
  - Voluntary hospices, many of which have been beacons of excellence in end of life care since the foundation of the modern hospice movement by Dame Cicely Saunders at St Christopher's Hospice in 1967.
  - The NHS End of Life Care Programme (2004–2007), which has contributed significantly to the rollout of programmes such as the Gold Standards Framework (GSF), Liverpool Care Pathway for the Dying Patient (LCP) and the Preferred Priorities for Care (PPC).
  - The Delivering Choice Programme currently being run by Marie Curie Cancer Care. This has highlighted the benefits of taking a whole systems approach to the delivery of end of life care.
  - Numerous examples of innovative practice, which have been provided during consultation on the strategy.

## Whole systems and care pathway approaches

9. The strategy was developed over a period of a year by an advisory board and six working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended. The care pathway involves the following steps:

- Identification of people approaching the end of life and initiating discussions about preferences for end of life care;
- Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;
- Coordination of care;
- Delivery of high quality services in all locations;
- Management of the last days of life;
- Care after death; and
- Support for carers, both during a person's illness and after their death.

### Key areas addressed by the strategy

10. The strategy sets out key areas, with the related actions and recommendations highlighted in bold throughout. These key areas can be summarised as follows.

### Raising the profile

11. Improving end of life care will involve Primary Care Trusts (PCTs) and Local Authorities (LAs) working in partnership to consider how best to engage with their local communities to raise the profile of end of life care. This may involve engagement with schools, faith groups, funeral directors, care homes, hospices, independent and voluntary sector providers and employers amongst others. **At a national level, the Department of Health will work with the National Council for Palliative Care to develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society.**

### Strategic commissioning

12. As the services required by people approaching the end of life span different sectors and settings, it is vital that an integrated approach to planning, contracting and monitoring of service delivery should be taken across health and social care. A strategic approach to commissioning led by PCTs and LAs is vital and commissioners are reminded of the requirement to conduct equality impact assessments of any planned changes to services. All relevant provider organisations should be involved in the commissioning process.

## Identifying people approaching the end of life

13. Caring for those approaching the end of life is one of the most important and rewarding areas of care. Although it is challenging and emotionally demanding, if staff have the necessary knowledge, skills and attitudes, it can also be immensely satisfying. However, many health and social care staff have had insufficient training in identifying those who are approaching the end of life, in communicating with them or in delivering optimal care. To address this, a major workforce development initiative is now needed, with particular emphasis on staff for whom end of life care is only one aspect of their work. This will include the provision of communications skills training programmes and other programmes based on the competences needed by different staff groups. Professional regulatory bodies and higher educational institutions will need to be engaged in this endeavour.

## Care planning

14. All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan. In some cases people may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Others may want to set out more general wishes and preferences about how they are cared for and where they would wish to die. These should all be incorporated into the care plan. The care plan should be subject to review by the multidisciplinary team, the patient and carers as and when a person's condition, or wishes, change. For greater effectiveness, the care plan should be available to all who have a legitimate reason to access it (e.g. out of hours and emergency services).

## Coordination of care

15. Within each local health economy mechanisms need to be established to ensure that each person approaching the end of life receives coordinated care, in accordance with the care plan, across sectors and at all times of day and night. PCTs will wish to consider the work from the Marie Curie Cancer Care Delivering Choice Programme. This demonstrates the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be coordinated. In addition, it is recommended that PCTs create locality-wide registers for people approaching the end of life, so that they can receive priority care. Currently there is a pilot testing this in Leeds.

## Rapid access to care

16. As the condition of a person may change rapidly, it is essential that services are marshalled without delay. If a person is likely to live for only a matter of weeks, days matter. If the prognosis is measured in days, hours matter. Therefore, PCTs and LAs will wish to consider how to ensure that medical, nursing and personal care and carers' support services can be made available in the community 24/7, including in care homes, sheltered and extra care housing and can be accessed without delay. From the emerging data from Marie Curie Cancer Care and others, it is evident that provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice.

## Delivery of high quality services in all locations

17. Commissioners will wish to review the availability and quality of end of life care services in different settings. These will include services provided in hospitals, in the community, and in care homes, sheltered and extra care housing, hospices and ambulance services. We expect PCTs to build upon current guidance, their baseline review of service provision and findings from their local reviews of end of life care carried out as part of Professor the Lord Darzi's NHS Next Stage Review. Also, commissioners will wish to refer to the quality standards, being developed in collaboration with Strategic Health Authorities (SHAs) End of Life Care Pathway Chairs, which set out what is needed to deliver high quality care at the end of life, adopting a care pathway approach. Consultation on these will commence shortly.

## Last days of life and care after death

18. Increasingly, the LCP, or an equivalent tool, is being adopted by those providing end of life services. The LCP, which was first developed for use with cancer patients, has now been successfully modified for use for people with other conditions. It can be used in hospitals, care homes, hospices and in people's own homes. For people who die suddenly, the care after death module is appropriate. The adoption of this tool is further supported by those hospitals who have participated in the National Care of the Dying Audit – Hospitals (NCDAH) based on the LCP.



## Involving and supporting carers

19. The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs. For many this will have been the first time they have cared for someone who is dying. They need information about the likely progress of the person's condition and information about services which are available. They may well also need practical and emotional support both during the person's life and after bereavement. Carers already have the right to have their own needs assessed and reviewed and to have a carer's care plan.

## Education and training and continuing professional development

20. Ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying will be critical to the success of improving end of life care. For this to happen, end of life care needs to be embedded in training curricula at all levels and for all staff groups. End of life care should be included in induction programmes, in continuing professional development and in appraisal systems.
21. The health and social care workforce can be segmented into three broad groups in relation to end of life care. Staff who spend the whole of their time caring for those at the end of life, those who frequently deal with end of life care as part of their role and those who care for people at the end of life infrequently. Developing core competences for each of these groups is work best led by organisations such as Skills for Care and Skills for Health, in collaboration with the Academy of Medical Royal Colleges. **SHAs will wish to consider how training can best be commissioned and provided to ensure that relevant staff have the necessary competences.**

## Measurement and research

22. Good information on end of life care is needed by patients, carers, commissioners, clinicians, service providers, researchers and policy makers. Each group will have somewhat different questions to ask and therefore different priorities for information. The NHS Choices website contains information which may be helpful.
23. Measurement of end of life care provision is a key lever for change and is essential if we are to monitor progress. This will require measurement of structure, process and outcomes of care. Structures and processes will largely

be measured through self assessment by organisations against the quality standards, on which consultation will commence shortly.

24. In addition to information on place of death, which is available through the Office for National Statistics (ONS), outcomes of end of life care will in future be monitored through surveys of bereaved relatives, national audits and regular reviews of complaints.
25. Development of this strategy has, wherever possible, taken account of the best available evidence, but has also revealed deficiencies in the evidence base. Working with charities and with other statutory funders, the Department of Health now wishes to enhance research into end of life care, especially for those with conditions other than cancer. A new one off initiative will build on the good foundations laid through the National Cancer Research Institute's supportive and palliative care research collaborative.

## Funding

26. It is difficult, if not impossible, to calculate the cost of end of life care in this country. This is partly because of the difficulty in defining exactly when end of life care starts. However, the key elements of expenditure can be identified. These are:
  - Hospital admissions;
  - Hospices and specialist palliative care services;
  - Community nursing services; and
  - Care homes.
27. Across health and social care, the overall cost of end of life care is large (measured in billions of pounds) and there is widespread agreement that these resources are not all being used as well as they might be. In addition, there are costs met by other government departments, such as the Attendance Allowance and Disability Living Allowance. There are also costs to unpaid carers.
28. As promised in the manifesto commitment, the government is committing increased resources to implement the strategy amounting to:
  - £88m in 2009/10
  - £198m in 2010/11

29. However, many of the improvements envisioned can be achieved by better use of existing health and social care resources. It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay. Further work on the cost impact of new end of life care service models, developed through the Marie Curie Cancer Care Delivering Choice Programme, is encouraging, showing a reduction in hospital admissions and increase in home deaths with stable overall costs.
30. However, in reviewing local areas, commissioners will need to consider the financial implications of:
  - Establishment of coordination centres/facilities;
  - Provision of 24/7 home care services;
  - Improved ambulance transport services for people near the end of life;
  - Additional specialist palliative care outreach services to provide advice and care for non-cancer patients and to increase input into care homes and community hospitals; and
  - Improved education and training of existing staff in care homes, hospitals and the community.

# What the End of Life Care Strategy means for patients and carers

Implementation of local end of life care visions, supported by this strategy, will mean that:

**You will have access to:**

- 1. The opportunity to discuss your personal needs and preferences with professionals who can support you. You will have the opportunity for these to be recorded in a care plan so that every service which will be involved in supporting you will be aware of your priorities. Your preferences and choices will be taken into account and accommodated wherever possible:**
  - All health and social care staff will be trained in communication regarding end of life care;
  - Health and social care professionals will be trained in assessing the needs of patients and carers and, where necessary, reconciling differing requirements; and
  - A care plan will be offered to every patient and carer, to help ensure services are provided to meet their needs and preferences.
  
- 2. Coordinated care and support, ensuring that your needs are met, irrespective of who is delivering the service to you:**
  - Every organisation involved in providing end of life care will be expected to adopt a coordination process, such as the Gold Standards Framework ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk));
  - Local end of life care coordination centres will be established to coordinate care across organisational boundaries; and
  - End of life care registers will be piloted and established to ensure that every organisation which will be involved in care is aware of a patient's wishes.

- 3. Rapid specialist advice and clinical assessment wherever you are:**
  - Patients and carers will have access to dedicated 24/7 telephone helplines and rapid access homecare services; and
  - Specialist palliative care outreach services will be established in every area.
- 4. High quality care and support during the last days of your life:**
  - A care pathway approach for management of the last days of life, such as the Liverpool Care Pathway ([www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway)), will be rolled out across England; and
  - Facilities will be provided to support relatives and carers who wish to stay with a patient in hospital.
- 5. Services which treat you with dignity and respect both before and after death:**
  - A major programme to provide training in end of life care for health and social care staff will be established.
- 6. Appropriate advice and support for your carers at every stage.**

**To support this, your services will be:**

- 7. Well planned and coordinated, ensuring you have access to the care you need, when you need it, irrespective of your condition or the setting in which you are being cared for, and that your choices are respected and will be taken into account:**
  - PCTs will develop comprehensive local strategic plans for end of life care, based on an assessment of the needs of the population they serve.
- 8. Quality assured and delivered to a high standard:**
  - Quality standards covering all providers of end of life care services will be developed (see Executive Summary paragraphs 17 and 24).

**9. Monitored and assessed to ensure quality. Best practice will be identified and spread so that others may benefit:**

- A national intelligence network will be established to collect, analyse and publish data on service quality performance; and
- A dedicated multiprofessional national support team will work with commissioners and providers to identify and spread good practice.

**10. Informed by the experience of others who have been in a similar situation to you. Equally your experience will help inform the care of future patients, leading to year on year improvements in quality:**

- Surveys of bereaved relatives and carers will be introduced, based on the successful Views of Informal Carers – Evaluation of Services (VOICES) programme;
- A comprehensive analysis of complaints relating to end of life care will be undertaken; and
- A national End of Life Care Research Initiative will be launched to further our understanding of how best to care for people reaching the end of their life and support those caring for them.



# **Part 1:**

# **Introduction**





# Chapter 1: The challenges of end of life care

## Introduction

- 1.1 Around 500,000 people die in England each year. The vast majority (around 99%) of deaths occur in adults over the age of 18 years, and most occur in people over 65 years. The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer, stroke, chronic respiratory disease, neurological diseases and dementia.
- 1.2 The age profile of people at the time of death and the relative frequency of different causes of death has changed radically since the start of the past century, when infectious diseases were the major killers in this country.
- 1.3 The place where people die has also changed markedly over the past century with most deaths no longer occurring at home but in hospital. Around 1900 about 85% of people died in their own homes, with workhouses accounting for most other deaths. By the mid twentieth century around 50% of people died at home. In the early twenty-first century acute hospitals have become the most common place of death.

## Challenges in end of life care

- 1.4 As a nation we face multiple challenges if we are to meet the needs and preferences of people as they approach death. In developing this strategy we have heard of numerous specific problems and concerns about end of life care, which can be summarised under the following headings:
  - As a society we do not talk openly about death and dying. Relatively few adults, including older adults, have discussed their own preferences for care with a close relative or friend, making it difficult for others to help ensure their wishes are met;
  - Health and social care staff often find it difficult to initiate discussions with people about the fact that they are approaching the end of their life. Death may be seen as a failure by clinicians, who may not have received training in how to have such discussions;
  - In the absence of open discussions it is difficult or impossible to elicit people's needs and preferences for care and to plan accordingly;

- People frequently need care from multiple services and they may need, or want, to transfer between locations (home, hospital, care home, hospice etc). Coordination of care is often poor;
- People who are approaching the end of life need access to care and support 24/7. Services in the community are sometimes unable to respond to these needs, resulting in people being admitted to hospital as an emergency rather than being cared for in their normal place of residence (home or care home);
- Even when services are available they do not always meet people's needs. In many cases this is felt to be due to inadequate training of health and social care professionals and other people involved in their care;
- When people enter the dying phase, health and social care professionals may not know what to do, or have the resources available, to ensure maximum comfort for the patient and support for carers;
- After someone has died, problems may arise with regard to verification and certification of death, viewing of the body and return of property to relatives, all of which can cause distress to the bereaved;
- Support for family and carers both during a person's illness and into bereavement is often inadequate. This can impact adversely on the carer's health and wellbeing and on their ability to provide care; and
- The additional needs of those with complex physical, learning or mental disabilities may not be identified, resulting in inadequate care.

1.5 As a result of these problems and deficiencies in service provision and professional practice, many people experience unnecessary physical, psychological and spiritual suffering and many do not live out their final days in the place of their choice. It can also influence the way family and friends cope during bereavement.

1.6 Some evidence of the magnitude of the problem related to the quality of care given at the end of life comes from a recent survey of complaints within the NHS, undertaken by the Healthcare Commission. Its 'Spotlight on Complaints' report assessed just over a total of 16,000 complaints made about NHS organisations between July 2004 and July 2006. Approximately half of these related to care given in acute hospitals. Of these, no less than 54% related in some way to end of life care. In its latest report 'Spotlight on Complaints 2' (April 2008) the Commission examined 50 cases where the primary complaint was about end of life care. These complaints were mainly about poor communication, lack of basic comfort, privacy and psychological

care and late or no referral for specialist palliative care. Relatives frequently commented that they seemed to be the first to recognise that the patient was dying. Inappropriate invasive procedures were often undertaken, even in the dying phase.

**Box 1: Keith's story – adapted from his wife's words – with permission**

Following surgery to remove an intestinal tumour, Keith developed an abscess that perforated necessitating him being ventilated and nursed on an intensive care unit. During this time his wife stayed with him constantly, sometimes sleeping in the hospital waiting room as there was nowhere else for her to stay.

Keith regained consciousness and when his condition stabilised he was moved back to a general ward. His wife was told that the bowel cancer had not spread and staff felt that he could return home within five days. However, Keith stopped eating and two days later his pain had increased significantly. His wife described spending hours one evening trying to speak to random doctors and nurses about his condition, before eventually returning home. The following day she phoned and was told that Keith had gone back to intensive care and was ventilated. Staff did not tell her that she could return to the hospital immediately and so she didn't, as previously she had been 'told off' for sleeping in the hospital waiting room.

Although not directly told, Keith's wife suspected that his life was limited. As a result she was unsure about contacting her four children. She also struggled with the decision about informing Keith's priest, as she did not want to alarm her husband but at the same time she knew he would wish to see a priest. She also felt upset and cheated that she had not been able to say goodbye to her husband before he was re-ventilated.

Keith's children were distressed to see their father connected to a ventilator and unable to speak. Keith's wife recalls the hospital staff saying that they would not resuscitate Keith if his heart stopped. However, she was not involved in any of these decisions and two days later Keith was still being given invasive treatments. Looking back, Keith's wife felt that had she been involved in decisions about his care she would have requested that unnecessary treatments should have stopped.

After a period, the hospital staff informed her that they had stopped giving Keith drugs, but they did not explain what would happen to Keith as a result. When she asked how she would know he had died, she was told to 'watch the equipment, when it reaches zero he will have died'. So, with her children, she watched until Keith died.

## Deaths in England

- 1.7 Over the past 20 years (1986 to 2006), the population of England and Wales has grown but the number of deaths per annum has fallen from 581,200 to 502,600 – a 13.5% decrease. Government Actuary Department statistics predict that the number of deaths will continue to fall until 2012. Thereafter, it is likely that there will be a steady increase in numbers of deaths – to 590,000 by 2030.
- 1.8 Long term projections undertaken by Gomes and Higginson<sup>1</sup> indicate that if the trend in home death proportions observed over the last five years continues, less than one in ten (9.6%) people will die at home by 2030. Institutional deaths would increase by over 20%. Deaths in institutions would rise from around 440,000 to around 530,000 per annum. People will die increasingly at older ages, with the percentage of deaths amongst those aged 85 and over rising from 32% in 2004 to 44% in 2030.
- 1.9 At present most deaths in England occur in NHS hospitals (58%), with deaths at home (18%) and in care homes (17%) collectively accounting for around 35% of all deaths (based on ONS figures for 2004). Hospices account for around 4% of deaths, with around 3% occurring in other locations.
- 1.10 There are some variations in place of death between regions with:
- Hospital deaths varying between 52.7% (South West) and 64.7% (London);
  - Care home deaths varying between 10.9% (London) and 22.1% (South West);
  - Home deaths varying between 16.9% (London) and 20.1% (North West); and
  - Hospice deaths varying between 2.5% (North West) and 5.9% (South East).

1 Gomes B, Higginson IJ. Where people die (1974–2030): Past trends, future projections and implications for care. *Palliative Medicine* 2008; **22**: 33–41.

- 1.11 There are some important differences in place of death between age groups:
- People dying in young adult life (15 to 44) or in their middle years (45 to 64) have the highest home death rates;
  - Children and those aged 75 to 84 have the highest hospital death rates;
  - Hospice death rates are highest for people aged 45 to 64; and
  - Care home death rates are highest in people over 85 years.
- 1.12 There are differences in place of death according to cause of death, which is interrelated with age at death. For example:
- Patients dying from cancer are much more likely than others to die in a hospice (around 16% vs. around 4% overall) and are less likely to die in an NHS hospital (50% vs. 58% overall); and
  - Patients dying from respiratory disease are more likely than average to die in hospital (67% vs. 58% overall).
- 1.13 The proportion of deaths occurring in hospitals varies significantly between countries. Sweden (62.5%), for example, has a higher hospital death rate than England (58%) and the Netherlands (34%) has a lower rate. The low number of people dying in hospital in the Netherlands is largely attributable to a higher proportion dying in care homes (34%), compared with 17% in England.

## People's preferences regarding place of death

- 1.14 Several large scale surveys of the public have been undertaken in recent years to ascertain people's preferences and priorities in relation to end of life care. These surveys are complemented by detailed research based on focus groups and interviews with older people and those who are approaching the end of life. Although people's preferences and priorities may change as death approaches, these changes will be linked on occasion to the concerns regarding the availability of services for their preferred place of care. The main findings can be summarised as follows:
- Most people would prefer to be cared for at home, as long as high quality care can be assured and as long as they do not place too great a burden on their families and carers;
  - Some research has shown that some people (particularly older people) who live alone wish to live at home for as long as possible, although they wish to die elsewhere where they can be certain not to be on their own;

- Some people on the other hand would not wish to be cared for at home, because they do not want family members to have to care for them. Many of these people would prefer to be cared for in a hospice; and
- Most, but not all, people would prefer not to die in a hospital – although this is in fact where most people do die.

## Potential for high quality end of life care

- 1.15 Although this work highlights the problems and deficiencies in current end of life care delivery, it is important to recognise that excellent care, which meets the needs of both the person who is dying and family members and carers, can be delivered in many different settings. The delivery of high quality end of life care can also be a major source of job satisfaction to health and social care professionals.
- 1.16 Much can be learned from the holistic approach to care which has been pioneered by hospices and specialist palliative care services in this country over the past 40 years. The pioneering work of the late Dame Cicely Saunders and others has shown what can be achieved through close attention to the physical, psychological, social and spiritual needs of patients and their families.
- 1.17 The challenge for the NHS and social care services now, is to extend this quality of care from the minority of patients (mainly those with cancer) who currently come into contact with hospices and specialist palliative care services, to all people who are approaching the end of life.

## The context and scope for an end of life care strategy

- 1.18 Over the last decade a substantial amount of work has been done internationally to increase the profile of end of life care. Both the World Health Organization and the Council of Europe have published documents highlighting the importance of palliative care. A number of countries have also developed work programmes and strategies to improve end of life care provision. These have included Australia (2000), Canada (2000) and New Zealand (2001). Each country has focused on access, integration of services, outcome measures, research and education. Experiences from these countries has informed and greatly contributed to our thinking.
- 1.19 The government's 2005 election manifesto stated that 'In order to increase choice for patients with cancer we will double the investment going into palliative care services, giving more people the choice to be treated at home.'

- 1.20 This commitment was extended in the *Our Health, Our Care, Our Say* White Paper in January 2006, and then in June 2006 with an announcement that an End of Life Care Strategy for Adults would be developed. At that point it was made clear that the strategy should not be confined to people with cancer, but should cover all conditions and all settings.

### The children's perspective

- 1.21 The strategy focuses on services for adults. A separate review of children's palliative care services, undertaken by Professor Sir Alan Craft and Sue Killen, was published in May 2007.<sup>2</sup> The review drew attention to the challenges facing palliative and end of life care services for children and set out a number of recommendations for government, as well as for the development of services at a local level. The recommendations were endorsed by the government and a first ever national strategy for children's palliative care – *Better Care, Better Lives* – was published in February 2008.
- 1.22 Whilst it is acknowledged that some parallels can be drawn between the principles applying to end of life care services for adults and those for children, it needs to be emphasised that there are also significant differences. For example, there are a wide variety of childhood conditions causing death before adulthood, many of which are rare. The time span of children's illnesses may also be different from adults, meaning that palliative care extends over many years. Moreover, children continue to develop physically, emotionally and cognitively, and this affects both their medical and social needs, as well as their understanding of disease and death. Above all, a child's death remains emotionally difficult, unnatural and unexpected for families and healthcare providers alike.
- 1.23 Due to advances in medical care, many children and young people suffering from life-limiting conditions likely to require palliative care are nowadays living longer, and many of them can maintain a good quality of life if they and their families are properly supported by services. However, they do require increasingly complex levels of support and it therefore becomes much more important that transitions to adult care are carefully considered by commissioners in planning end of life care services.

### The legal framework

- 1.24 The strategy has been developed within the current legal framework. Whilst the debate about changing the law to allow euthanasia and assisted suicide

2 *Palliative Care Services for Children and Young People in England*. Craft/Killen, 2007



will continue in this country and elsewhere, these issues are beyond the scope of this strategy.

- 1.25 An important element of the existing legal framework is the Mental Capacity Act, which came fully into force in October 2007. The Act extends the ways in which people can plan ahead and set out in advance what they would like to happen should they be unable to make decisions about their care in the future.

### Building on a firm foundation

- 1.26 This country has some of the best hospice and specialist palliative care services in the world, many of which are managed and predominantly funded by the voluntary sector. These services provide inpatient care, day care, community based care and care in acute hospitals. Specialist palliative care services often lead research and development agendas, as well as being major providers of education in end of life care.

**Table 1: Adult inpatient specialist palliative care units, England, 2008**

	Units	Beds
NHS	42	504
Voluntary	133	2141
Total	175	2645

Source: *Hospice and Palliative Care Directory 2008*

**Table 2: Adult community and hospital support services, England, 2008**

	England
Home Care services	231
'Hospice at Home' services	93
Day Care services	225
Hospital Support Nurses	29
Hospital Support Teams	226

Source: *Hospice and Palliative Care Directory 2008*

- 1.27 The *NHS Cancer Plan* (2000) and the majority of the National Service Frameworks emphasise the importance of palliative or end of life care. The *NHS Cancer Plan* set out the commitment to increase expenditure by the NHS on specialist palliative care services by £50m pa by 2004. This commitment

recognised the fact that for too long the NHS had regarded specialist palliative care as an optional extra and that the NHS had relied too heavily upon the goodwill and funding of charities. This funding has been delivered.

1.28 In 2003 the *Building on the Best* White Paper set out plans to improve choice within the NHS. Included within this was a commitment to spend £12m over three years on a programme to improve end of life care. This programme, which has run from 2004 to 2007, involved all 28 Strategic Health Authorities (SHAs) then in existence and focused attention beyond specialist palliative care.

1.29 The main aims of the NHS End of Life Care Programme were:

- To encourage local adoption and development of end of life care models to address the needs of the local population, in particular the Gold Standards Framework (GSF), Liverpool Care Pathway for the Dying Patient (LCP) and the Preferred Priorities for Care (PPC) (see chapters 3 and 4); and
- To engage care homes in improving end of life care, through adaptation of these models (see chapter 4).

The NHS End of Life Care Programme has exceeded its own goals in every setting. However, the coverage levels for January 2008 show how much more needs to be done.

**Table 3: NHS End of Life Care Programme (2004 to 2007) – Roll out of GSF, LCP and PPC and other locally developed models**

Care setting	Anticipated level of coverage by end 2007	Coverage at June 2005 (baseline)	Coverage at January 2008
Primary care	60% of practices will have implemented one or more tools	23%	75%
Acute Trusts	80% of Trusts will have implemented one or more tools on three or more wards.	49%	85%
	4% of Trusts will have implemented one or more tools on all appropriate wards	0%	17%
Community hospitals	20% of community hospitals will have implemented one or more tools	9%	47%
Care homes	4% of care homes will have implemented one or more tools	0.3%	7.6%
Hospices	Hospices are encouraged to implement LCP	36%	75%

1.30 The development of the End of Life Care Strategy also built on recent experience from the Delivering Choice Programme run by Marie Curie Cancer Care. This programme is currently running pilots in Lincolnshire, Tayside, Leeds, Barnet and South East London, with two planned to follow in Somerset and Tyneside.

1.31 The Delivering Choice Programme has highlighted the benefits of:

- Taking a 'whole systems' approach, ensuring that improvements to particular elements of the delivery of care are not mitigated by problems elsewhere in the system;

- Bringing senior representatives of all relevant commissioning and provider organisations together to plan services across a locality;
- Having a central coordinating function to ensure that people get the services they require from all the different providers; and
- Providing rapid services in the community on a 24/7 basis, to avoid unnecessary hospital admissions.

1.32 During the development of the strategy, the Department of Health received information on many other innovative services. Some of these are highlighted in relevant chapters in this strategy and can also be found at [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

### **Aim of this end of life care strategy**

1.33 In the past, the profile of end of life care within the NHS and social services has been relatively low. Reflecting this, the quality of care delivered has been very variable. The aim of this strategy is to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.

1.34 This aim can be achieved through the following ten objectives:

- To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality;
- To ensure that all people are treated with dignity and respect at the end of their lives;
- To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life;
- To ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care;
- To ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible;

- To ensure that the many services people need are well coordinated, so that patients receive seamless care;
- To ensure that high quality care is provided in the last days of life and after death in all care settings;
- To ensure that carers are appropriately supported both during a patient's life and into bereavement;
- To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care; and
- To ensure that services provide good value for money for the taxpayer.

## Development of the strategy

1.35 Development of the strategy was overseen by an Advisory Board, chaired by Professor Mike Richards. The Board was supported by working groups related to:

- The end of life care pathway;
- Care homes;
- Workforce development;
- Measurement;
- Levers for change; and
- Costs and analysis.

1.36 In addition to this, a broad consultation was held with key stakeholders from the voluntary sector, the NHS and social care. A number of specific consultation events were also held with key groups and organisations, including: leaders of different faith groups, carers' organisations, hospices, researchers and research funding organisations, Connecting for Health, as well as a range of stakeholders identified through the Equality Impact Assessment, such as black and minority ethnic groups. In total, several hundred people, representing a broad range of interests and organisations, have contributed to the development of the strategy.

## The health reform agenda

- 1.37 The End of Life Care Strategy aligns with the NHS reform agenda, which focuses on devolved funding and decision making and local service development.
- 1.38 End of life care was included in the NHS Operating Framework 2007/08 through which Primary Care Trusts (PCTs), working with local authorities, were asked to conduct a baseline review of local services. It was also included in the NHS Operating Framework for 2008/09, with an emphasis on improving access to high quality, coordinated services close to home.
- 1.39 Emerging themes from the national strategy were shared with the End of Life Care Clinical Pathway chairs for each SHA. The SHA clinical pathway chairs gave valuable feedback from their local discussions, which enhanced the development of the final strategy.



# Chapter 2: Death, dying and society

## Introduction

- 2.1 There is now much less familiarity with death and dying than in previous centuries. Many people will not have had to deal with a close family member or close friend dying until they are into their mid-life years, and some will not have seen a dead body until this time. Most deaths occur in institutions, for example, hospitals and care homes and are therefore removed from people's direct experience.
- 2.2 The reality of death and dying is rarely discussed in modern society. Many consider death to be the last great taboo in our society and there is evidence to show that most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life. In one recent survey, conducted by Marie Curie Cancer Care, almost four out of five respondents felt that death is a taboo subject for the majority of people in this country. In another survey, conducted in Norfolk and Waveney, two thirds of respondents felt that, as a society, we do not discuss death enough. In a third large scale survey, conducted on behalf of the BBC, only 34% of the general public reported that they had discussed their wishes for how they would like to die. Even among those over 65 years the figure was only 51%. In contrast, two thirds of people over 65 years had prepared a will.

## The consequences of lack of openness and discussion about death and dying

- 2.3 During the development of this strategy experts told us that changes to the way in which society views death and dying have contributed to changes in the experience of people receiving end of life care, as well as that of their carers. Promoting a better understanding of death and dying will therefore be an important part of delivering this strategy.
- 2.4 The lack of openness and discussion about death and dying has adverse consequences:
- People may be unnecessarily frightened about the process of dying;
  - Close relatives of people who are approaching the end of life may be unaware of their wishes and therefore how best to help and support



them. This is particularly important for those who may lose the capacity to make their own decisions;

- Inappropriate interventions may be tried if those caring for someone are not aware of the person's treatment preferences, including advance decisions to refuse treatment;
- People who would have wished their organs to be used for transplantation may not have discussed this with relatives who have to make decisions after their death;
- People may not have discussed funeral wishes with their relatives;
- People may die without writing a will;
- Same sex partners may not have declared their status, with the consequence that professionals may exclude them from involvement in their partner's care;
- Fear of the unknown means that people sometimes tend to avoid those who are ill for fear of 'upsetting them' or 'making them worse';
- Lack of public and professional discussion about death and dying may be one of the reasons why this area has historically been given low priority by health and social care services;
- People, including clinical staff, are ignorant of the possible options that could improve quality of life and restore independence;
- Lack of knowledge of the financial implications for the bereaved following a death and what needs to be put in place ahead of the event; and
- Lack of public and professional discussion about grief and loss, which results in the isolation of the bereaved.

## **National and local action to promote public awareness and change attitudes about death and dying**

- 2.5 This strategy sets out the government's intention to make end of life care a priority. However, government action alone cannot change attitudes towards death and dying, nor raise awareness of the issues involved.
- 2.6 Experts have told us that the general public, professionals, independent groups, voluntary sector and statutory organisations will need to work together in partnership to deliver improved awareness of the issues involved with end of life care and to change attitudes. This will require concerted action and progress will not be made overnight.

- 2.7 **The National Council for Palliative Care (NCPC) has agreed to lead a broad based national coalition of organisations, building on the involvement and commitment of the wide range of stakeholders who contributed to this strategy, in promoting greater public discussion and awareness of issues involved with death and dying. The government is committed to playing an active role in this coalition, including providing financial support.**
- 2.8 At a local level, raising the awareness of death and dying can be taken forward by a variety of organisations. For example:
- Funeral directors can hold open days encouraging the general public to see their premises, the equipment and processes involved in arranging and conducting funerals;
  - Crematoria can hold events which address some of the misconceptions people hold about what happens;
  - Religious organisations such as churches, mosques, synagogues etc can play a significant role in promoting understanding and information;
  - Solicitors could prompt people to think about their preferences for end of life care when assisting them with making a will;
  - Schools, universities and other education providers can help introduce discussions about death, dying, grief and loss and so sensitise people at an earlier age and empower communities and neighbourhoods to be supportive;
  - Employers can provide information, for example through payroll notices; and
  - Hospices can reach out to their local communities. For example, St Peter's Hospice in Bristol works with local school children and teachers in dealing with grief and bereavement issues.

**Box 2: St Christopher's Hospice: engaging with school children**

St Christopher's Hospice Creative Living Centre and the Candle Project run a partnership project with primary schools within the hospice's catchment area. The aim of the project is to introduce the hospice to Year 5 school children in a creative and non-threatening way and to promote healthier attitudes to death and dying amongst them, their teachers and school peers and also to parents and carers. This programme has also been extended to a local city academy working with Year 12 students.

Outcomes include:

This project has demonstrated how a local hospice can have a wide and positive influence in awareness rising. Significantly the number of schools involved has doubled to twelve and 80% of local schools refer children to the Candle Project which provides specific support to bereaved children.

A number of children and parents are now involved in talking about the work of the hospice and in fundraising.

Funding to support this project has been received from The Daisy Foundation and the Arts Council.

**Contact details:** Nigel Hartley, Director, Creative Living Centre/Candle Project Leader. [n.hartley@stchristophers.org.uk](mailto:n.hartley@stchristophers.org.uk) ([www.stchristophers.org.uk](http://www.stchristophers.org.uk)).

**Box 3: St Joseph's Hospice: engaging with local ethnic communities**

St Joseph's Hospice in East London serves a highly diverse and changing population. Working with Social Action for Health, a local community development organisation, a dialogue has been established between the hospice and local ethnic communities.

By spending time at the hospice, staff from Social Action are then able to work with mosques, local community centres, social clubs and schools to talk about the work of the hospice. They have opened up discussions about people's experiences, anxieties and aspirations with regard to end of life care, which are then fed back to hospice staff enabling them to consider how to develop services which are sensitive to the needs of the wider population.

This creates a physical environment that is perceived as welcoming by ethnic communities who wish to use the hospice. Information about the services the hospice provides is available in new forms, including via local radio. A drop-in centre is being planned to provide advice and support, and hospice staff and volunteers are receiving training and support in providing care that is culturally sensitive.

**Contact details:** Heather Richardson, Director of Care Services, St Joseph's Hospice. H.Richardson@STJH.org.uk

- 2.9 Such activity should not take place in a vacuum and local organisations should be able to receive support from their local Primary Care Trust (PCT). **To facilitate this, PCTs should include strategies for promoting awareness and discussion of issues relating to dying, death and end of life care in comprehensive local strategic plans for end of life care, based on an assessment of the needs of the population they serve. This might be usefully linked with joint strategic needs assessments.**



# **Part 2:**

## **Care delivery**



# Chapter 3: The end of life care pathway

## Introduction

- 3.1 Over the past few years the concept of a care pathway has been found to be useful for the planning, contracting and monitoring of services across a wide range of conditions. In this chapter the concept is applied to end of life care.
- 3.2 Individuals differ in many ways as they approach the end of life. No two people will have an identical end of life care pathway. For each individual many different factors will impact on their needs and preferences for care. These include:
- The nature of the condition, or conditions, from which they are suffering and the different symptoms that they cause. Different diseases have different trajectories at the end of life. Many older people have several coexisting health problems;
  - Living arrangements, for example, whether they live alone or with others, the proximity of close family, in sheltered and extra care housing accommodation, in a care home etc;
  - Social circumstances, e.g. poverty, refugee and asylum seeker status;
  - Pre-existing vulnerabilities, such as mental health and learning disabilities;
  - Experience of health care to date, particularly in relation to the deaths of others;
  - Approach to life and psychological wellbeing;
  - Cultural factors; and
  - Spiritual/religious beliefs.

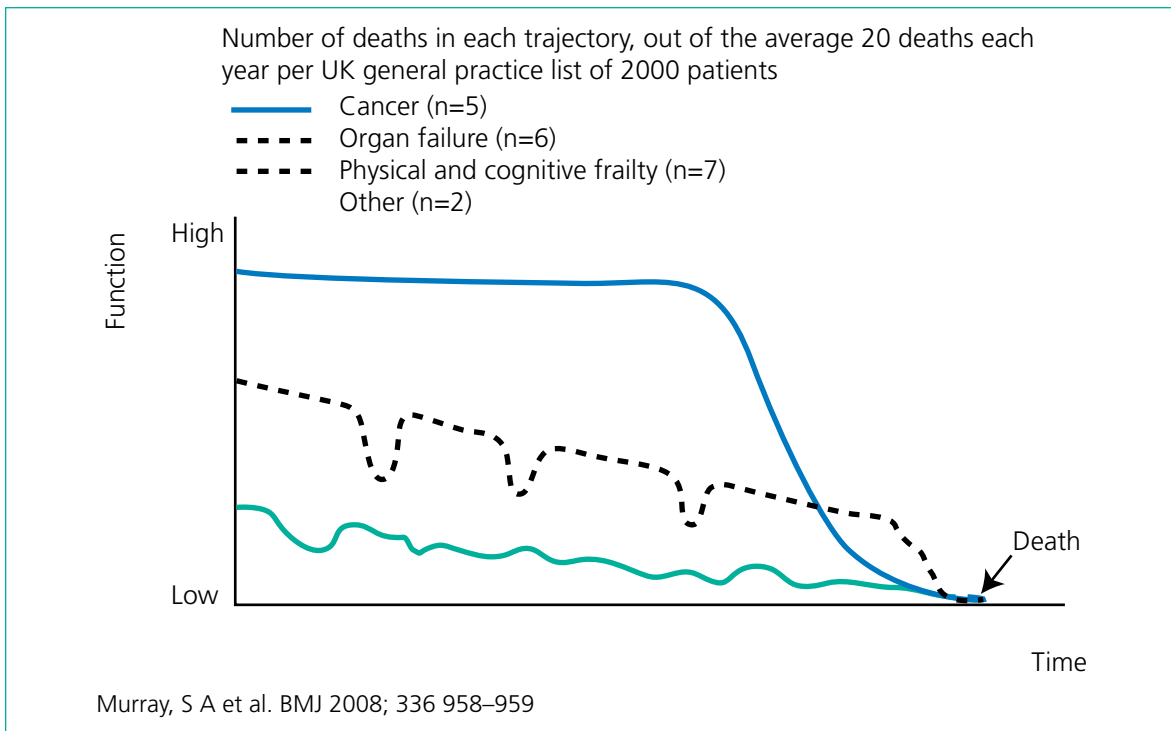
## Trajectories of decline at the end of life

- 3.3 Some people with long term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life. Others will experience a more gradual decline, interspersed with episodes of acute ill health from which they may, or may not, recover. A third group are very frail for months or years before death, with a steady progressive decline.

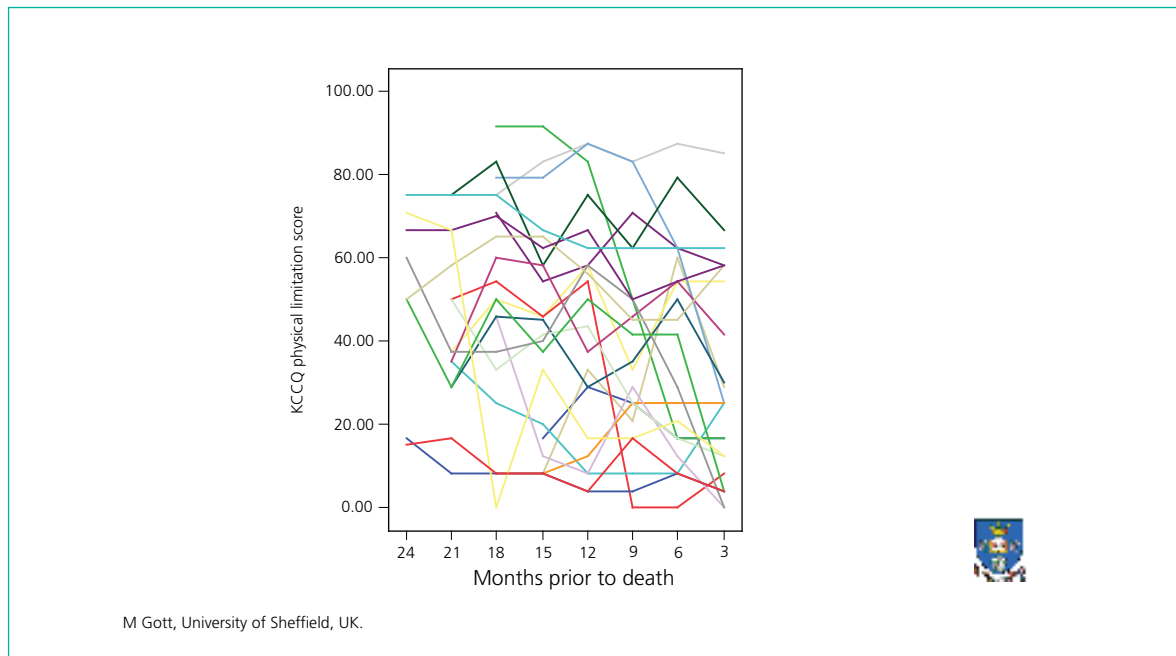


- 3.4 These three patterns, or trajectories, are illustrated in Figure 1. Some authors have suggested that the first pattern may be typical of cancer, the second may be typical for people with organ failure (e.g. those with heart failure or chronic obstructive pulmonary disease), and the third may be typical for people with dementia.
- 3.5 However, empirical evidence from a cohort of patients who died of a variety of conditions over a two year period indicates that the picture is more complex (Figure 2).

**Figure 1: The three main trajectories of decline at the end of life**



**Figure 2: Kansas City Cardiomyopathy Questionnaire (KCCQ) physical limitation scores of 27 patients for 24 months prior to death**



- 3.6 There is no simple way to define the start of the end of life care pathway. A suggested definition for end of life care based on work by the National Council for Palliative Care is shown in Box 4.

#### **Box 4: A Working Definition of End of Life Care**

##### **End of life care is care that:**

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

**Source:** National Council for Palliative Care 2006

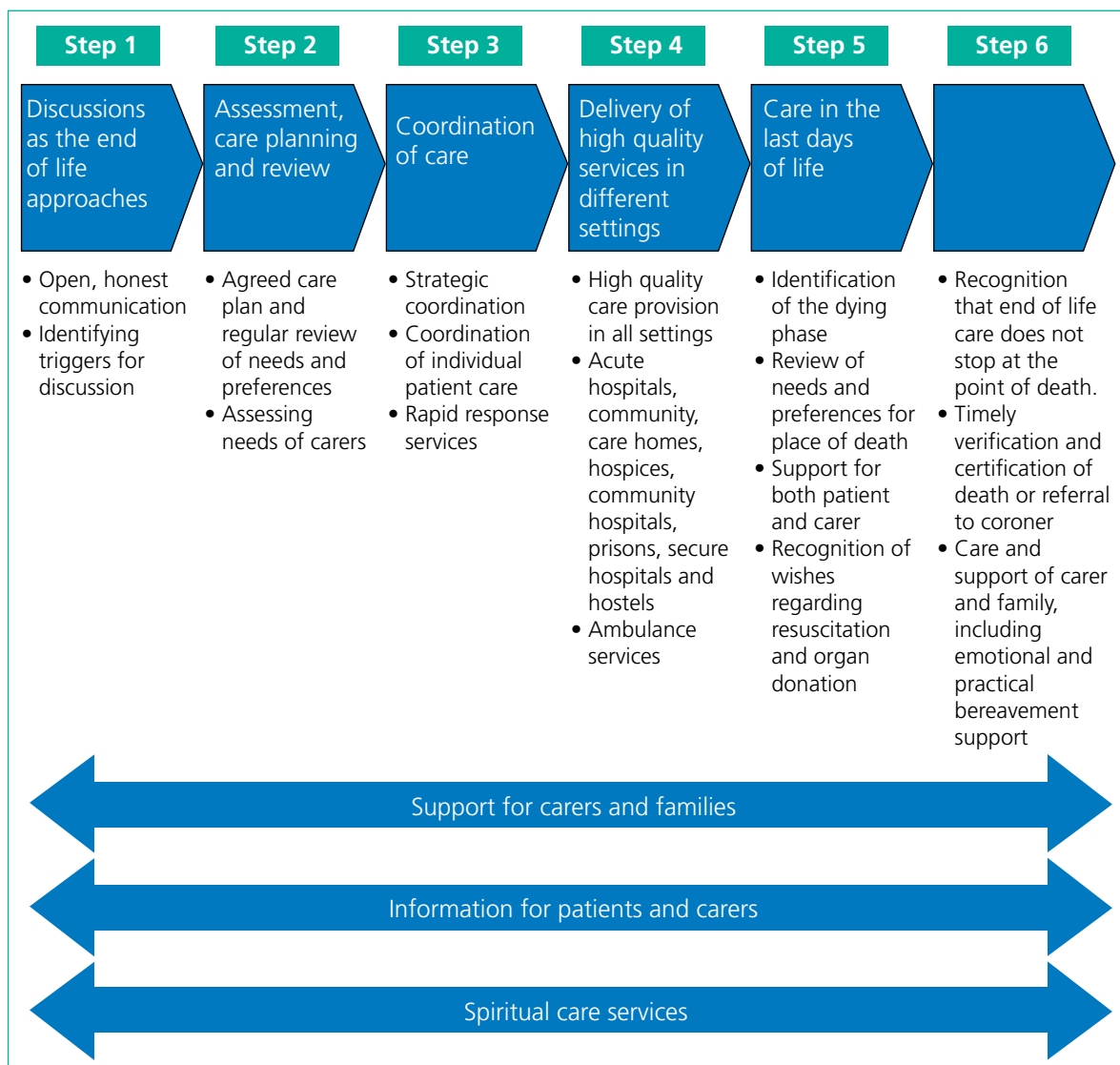
- 3.7 The definition of the beginning of end of life care is variable according to individual person and professional perspectives. In some cases it may be the person who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the person. In all cases, subject to the person's consent,

the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

- 3.8 For some the start may be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease. For others it will be at a point when there is a deterioration in a chronic illness and it becomes apparent that the likely prognosis is measured in months or possibly a year or two, for example a patient experiencing an acute episode on the background of longstanding chronic obstructive pulmonary disease. Some conditions, such as heart failure, have such a variable prognosis that whilst one patient may die within months of diagnosis another may survive for many years.
- 3.9 Alternatively, it could be an elderly person who is becoming increasingly frail and recognises that they need increased help to continue living at home, or makes the decision to become a resident of a care home or of sheltered or extra care accommodation.
- 3.10 It is important to remember that death may be sudden or violent, or as a result of a sudden outbreak of infectious disease that spreads rapidly through the population. In the latter case, whilst the NHS may have plans in place to be able to deal with such a pandemic, it is important to note the impact it may have on the provision of other services such as death certification, availability of coroners etc and the effect it will have on families' and carers' support requirements. It is essential that end of life care services are adaptable to all these scenarios.
- 3.11 Despite all these differences the following key elements of an end of life care pathway have been recommended during the development of this strategy:
- Step 1 Discussions as the end of life approaches;
  - Step 2 Assessment, care planning and review;
  - Step 3 Coordination of care for individual patients;
  - Step 4 Delivery of high quality services in different settings;
  - Step 5 Care in the last days of life; and
  - Step 6 Care after death.
- 3.12 Alongside all of these steps attention also needs to be given to:
- Support for carers and families;

- Information for patients and families; and
- Spiritual care for patients and families.

**Figure 3: The End of Life Care Pathway**



3.13 It is important to consider the support, care and information that is required by the person's family and caregivers both during the illness and into bereavement. Similarly, spiritual care and support for both the person and their carers is integral to the end of life care pathway.

3.14 When death follows a short acute illness steps 5 and 6 of the care pathway are relevant. Following a sudden death the pathway begins at step 6 (care after death).

- 3.15 In this strategy we make a distinction between coordination of care for the individual, and strategic coordination, which involves the planning and monitoring of service delivery across a population. Strategic coordination at the local level should be led by Primary Care Trusts (PCTs) working in partnership with Local Authorities (LAs), and should involve close cooperation with all relevant service providers. Strategic coordination is covered in more detail in chapter 8.

### **Step 1: Discussions as the end of life approaches**

- 3.16 One of the key aims of an end of life care strategy is to ensure that services provided to people approaching the end of their lives are, as far as is possible, responsive to their needs and preferences. To achieve this aim it is clearly essential that those responsible for providing care should be aware of the needs and preferences of each individual.
- 3.17 People also need to be given the opportunity to consider what care they wish to receive, based on the best available information about what may lie ahead of them and what services are available. It also needs to be recognised that some people will not wish to confront their own mortality and will not wish to enter into conversations either with their families or with health and social care staff. If this is their choice, it should be respected.
- 3.18 During the development of this strategy many people have identified the lack of open discussion between health and social care staff and those approaching the end of life and those who care for them, as one of the key barriers to the delivery of good end of life care. However, it has also been recognised that rectifying this represents a major challenge. It will require a significant culture shift both amongst the public and within the NHS and social care. Clinicians and managers need to accept that death does not always represent a failure of healthcare and that enabling people to die as well as possible is one of the core functions of the NHS.
- 3.19 A change in culture will not happen overnight. Rather it will require sustained efforts from a wide range of opinion leaders in Royal Colleges, professional societies and from senior managers in PCTs, NHS Trusts and LAs. It will also require the involvement and support of regulators, of the NHS, social care and of the professions. The Mental Capacity Act, which came fully into force in October 2007, may also encourage greater willingness to initiate discussions.

- 3.20 If open discussions between health and social care staff and people under their care are to become a reality we need to develop a consensus on:
- When discussions should occur;
  - Who should initiate the discussions; and
  - What competences are required for these discussions and how staff can best be trained.
- 3.21 There will never be a single fixed point at which it is right to initiate discussions about end of life issues and it should not be assumed that the person will not raise the subject themselves. For many people this will be an iterative process. The process may start even before they have a life threatening illness – for example a discussion with a GP after the death of a loved one.
- 3.22 For many people suffering from a chronic illness a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The *Prognostic Indicator Guidance* (June 2006) developed as part of the Gold Standards Framework (GSF) provides useful prompts or ‘triggers’ to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened. Further work to achieve consensus on trigger points is needed amongst professional and patient groups.  
([http://www.goldstandardsframework.nhs.uk/content/gp\\_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%2025.pdf](http://www.goldstandardsframework.nhs.uk/content/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%2025.pdf))
- 3.23 Some healthcare professionals find it useful to ask themselves the ‘surprise’ question: ‘Would I be surprised if the person in front of me was to die in the next six months or year?’ If the answer to this is that they would not be surprised they may want to ask themselves further questions, such as ‘Is the patient likely to be aware of this?’ and ‘Who would be best placed to initiate discussions on the end of life?’ It is also suggested that clinicians should ask themselves, as they assess a new admission to hospital, about the likelihood of death occurring during that admission.

**Box 5: Understanding chronic obstructive pulmonary disease (COPD) patients' decisions regarding future treatment**

Discussions about end of life treatment need to be carefully tailored to individual needs, according to a study of COPD patients by the National Heart and Lung Institute at Charing Cross Hospital.

The study, involving three focus groups of patients whose condition had led to hospitalisation, discovered how far patients wished to be involved in decisions about end of life care. The study revealed that patients had mixed views about when it was appropriate to discuss future treatment and some were in denial about their disease.

However, most felt it was clearly inappropriate to discuss these issues when they were ill and in hospital.

The authors suggest the best time for this conversation might be at the first review after discharge and this could be aided if patients were given some material in advance to help them think about the issues. A leaflet containing helpful information about end of life issues is currently being designed and tested within the Imperial College NHS Healthcare Trust.

The study indicates that communication between doctors and patients is often 'sub-optimal' but most patients said they would prefer to discuss end of life issues with their consultant, GP or a respiratory nurse.

The study was funded by the North West Strategic Health Authority End of Life Care project.

**Contact details:** [m.partridge@imperial.ac.uk](mailto:m.partridge@imperial.ac.uk)

- 3.24 The trigger for a discussion about the end of life may not necessarily be purely related to a clinical event or deterioration. Changes in social circumstances, such as a move from independent living to sheltered or extra care accommodation, or into a care home, may also be a suitable time to initiate discussions.
- 3.25 The range of different circumstances when it may be appropriate to initiate discussions means that this cannot and should not be the remit of one professional group alone. In many cases, the person's GP will be the appropriate person, as he/she is likely to have known the person for years

and to be aware of their medical history and social circumstances. However, hospital clinicians and senior staff in care homes may also be the appropriate people to initiate discussions.

- 3.26 All health and social care staff who may need to initiate discussions about the end of life need to have the necessary knowledge, skills and attitudes. Without these the experience can be distressing both for the person and the member of staff. At whatever point the discussion takes place, it needs to be honest and open, with staff checking what the person understands, how much they wish to know and whether other family members should be present. Communication skills training and workforce issues more generally are covered further in chapter 6.
- 3.27 **Good PCTs, working with LAs, will wish to ensure that relevant staff receive training in communication skills in order to be equipped and confident in initiating conversations and supporting people approaching the end of life.**
- 3.28 **Health and social care staff who are likely to be involved in discussions about end of life issues should ensure that they have the relevant competences.**

## Step 2: Assessment, care planning and review

- 3.29 Too often a person's needs and those of their family and carers are not adequately assessed and addressed. Whatever triggers the discussion with an individual about end of life care planning, an holistic assessment should be undertaken which covers the full range of physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs.
- 3.30 Such an assessment serves to identify any areas of unmet need and/or the need to involve other practitioners. For example, where a person is not already eligible for NHS Continuing Healthcare, the factor that triggers the assessment, such as a deterioration in condition, or moving into a care home providing nursing care, will usually also prompt a consideration of whether the person is, or is likely to become, eligible for NHS funding. When a person goes into a care home, the person's financial position and eligibility for benefits should, therefore, also be explored.
- 3.31 The person's preferences regarding both the type of care they would wish to receive and the setting or location in which they wish to be cared for should also be elicited. Advance care planning (ACP) is a very helpful way of



achieving this and this is set out clearly in *Advance Care Planning: a guide for health and social care staff* (February 2007). As this document points out, it is important to understand the role of an advance care plan and the Mental Capacity Act (MCA) 2005. The outcome of the ACP may be the completion of a statement of the person's wishes and preferences about their future care, or an advance decision to refuse specific treatment. The MCA gives people specific ways to plan ahead in terms of their care or treatment for a time when they may lack capacity. People do not need to plan in this way if they do not want to. Alternatively, an individual may decide to appoint a person to make treatment decisions on their behalf by authorising the person to do so under a Lasting Power of Attorney.

- 3.32 A financial assessment should be included within the assessment, particularly in relation to benefits and entitlements.

**Box 6: The Preferred Priorities for Care  
(formerly Preferred Place of Care)**

The Preferred Priorities for Care (PPC) is a document that individuals hold themselves and take with them if they receive care in different places. It has space for the individual's thoughts about their care and the choices they would like to make, including saying where, if possible, they would want to be when they die. Information about choices and who might be involved in their care can also be recorded, so any care staff can read about what matters to the individual, thereby ensuring continuity of care. If anything changes, this can be written in the plan so it stays up to date. It is never too early to start a PPC plan.

Individuals can initiate the PPC at any time and this will help staff follow their wishes in making best interest decisions if the individual loses capacity towards the end of their life.

**Contact details:** [www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred\\_Priorities\\_for\\_Care\\_V2\\_Dec2007.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf)

**Box 7: The Preferred Priorities for Care – a case study**

Tony had chronic renal disease stretching over 20 years. Following an unsuccessful transplant, he was maintained on home dialysis. He had also lost a limb as a result of his disease.

Using the PPC document the staff discussed with him what he felt his needs and preferences were for care. Tony was quite clear what he wanted and was happy to talk these over with his wife and family.

Having discussed things with his wife, he asked staff to help him complete the document. Using his own words, this described how he felt that he had had a good innings and that he did not want to be resuscitated if he 'went off', and that if he became too ill to continue dialysis he wanted to die at home or in a hospice. This was discussed with the doctor and it was documented in his notes.

Tony was subsequently admitted to another hospital having deteriorated over a matter of weeks. He was diagnosed with a chest infection and his condition was very poor. Tony and his family were able to discuss the PPC document with the staff, enabling everyone to be aware of what he wanted.

His nurse reported that the PPC process had enabled her to have an easier conversation with the family as she already knew what the patient wanted, and that it was a great tool to aid end of life discussions.

Although Tony died in hospital which was not his first place of choice, he had contributed to the decision and accepted that hospital was more appropriate than home. His family were happy and felt that the staff had ensured privacy and dignity for him.

**Contact details:** [www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred\\_Priorities\\_for\\_Care\\_V2\\_Dec2007.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf)

- 3.33 At the opposite end of the spectrum some people are subjected to numerous assessments by different health and social care staff, without apparent reference to records of other assessments. This can lead to frustration and exhaustion, for both the person and their carers, and is indicative of poorly coordinated services and inefficient processes. In addition, it will be important to remember that people with long term conditions may already have a

care plan in place and any plan relating to end of life care will need to be sufficiently flexible to be able to join up with it.

- 3.34 Following an initial assessment a person's clinical condition will inevitably change, as may the level of support provided by the family. The person's needs and preferences and their care plan should therefore be subject to regular review.
- 3.35 Carers should always have their views listened to and taken into account. LAs have a duty to inform carers of their right to a carer's assessment to determine support needs. The assessment should be reviewed at regular intervals or when changes occur. Carers' assessments should include their physical, emotional, psychological, financial and social needs (including any need for support to maintain employment, participate in education or pursue leisure interests) as well as their ability to continue providing care. This is covered in more detail in chapter 5.
- 3.36 A number of models to support holistic assessment are already in place, the Single Assessment Process (SAP) for older people being one example. Following publication of the White Paper, *Our health, our care, our say* (2006) the Department of Health is developing a Common Assessment Framework (CAF) for adults which will build on the SAP and the Care Programme Approach (CPA). As part of this work, the Department of Health is developing proposals to explore the scope for improving information sharing and access between the NHS and social care staff, and more widely with organisations providing community care/support.

**Box 8: Cedar Court**

Cedar Court is a care home with 52 residents (nursing) in Leicestershire. It has established a register of residents in order to identify, assess and plan for future needs using ACP. This is done with the involvement of both the residents and their families. The results have been striking in terms of improving communication between staff and fostering greater teamwork, and in the quality of care and coordination with the GP practice, which in turn has led to fewer hospital admissions in the last stages of life.

**Contact details:** Tel: 0116 257 1330  
cedarcourt2@shealthcare.co.uk

- 3.37 **All people approaching the end of life, and their carers, should be entitled to:**
- **Have their needs assessed by a professional or professionals with appropriate expertise;**
  - **Have a care plan which records their preferences and the choices they would like to make. The care plan should be reviewed as their condition changes;**
  - **Be involved in decisions about treatments prescribed for them, including the option to say 'no' to treatments they do not wish to have prescribed; and**
  - **Know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff with their permission.**
- 3.38 **Those who assess patient and carer needs should have reached an agreed level of competence in aspects of the assessment process. They should also have access to up to date information about local service providers, referral criteria and support services.**
- 3.39 **Care plans, including the person's preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them, including out of hours and emergency/urgent care services. Holding the plan electronically will facilitate this. All care plans should be regularly reviewed and updated.**

### **Step 3: Coordination of individual patient care**

- 3.40 Once a care plan has been agreed, it is essential that all the services which the person needs are effectively coordinated. As a person's condition may change rapidly it is also imperative that services are marshalled without delay. If a person is likely to live for only a matter of weeks, days matter. If the prognosis is measured in days, hours matter.
- 3.41 People may require services from multiple agencies and in different settings at different times, for example hospital, home, care home or hospice. Coordination of all the relevant services is a major activity in itself. It can be time consuming, especially if individual members of staff are not fully familiar with all the other service providers. If the responsibility for coordinating service delivery falls on an individual nurse it can take them away from direct delivery

of care to patients. Lack of coordination can lead to people dying in a place which is not of their choosing.

3.42 Coordination of the care needs of individuals at the end of life and their carers needs to be considered at several levels:

- Coordination within an individual team, for example primary care;
- Coordination between teams working within a single institution, for example a cancer team and a specialist palliative care team; and
- Coordination across organisational boundaries.

Each of these levels matter, but different arrangements may be appropriate.

3.43 One example of how some of these issues have been addressed is the GSF, which provides an approach to coordination of care within an individual team or location. The GSF was first developed to improve the quality of end of life care within general practice. It has now been successfully modified as a possible approach for use in other settings. Further details on the GSF are given in the relevant sections of chapter 4.

3.44 Coordination between teams can be achieved in several different ways:

- Members of one team may attend meetings of another team, for example a specialist in palliative care attending a COPD team meeting; and
- Systems may be put in place to alert hospital teams which have previously been involved in a person's care when that person is re-admitted to hospital. The Recurrent Admission Patient Alert (RAPA), developed at Sherwood Forest NHS Foundation Trust, is one example of this. Although originally developed for cancer patients, the principles are now being transferred to meet the needs of patients with other conditions.

3.45 To improve coordination across organisational boundaries, Marie Curie Cancer Care has piloted the development of a dedicated coordination centre which covers most of the population of Lincolnshire.

**Box 9: The Marie Curie Cancer Care Delivering Choice Programme**

Initiated in 2004, the programme aims to improve the way palliative care is delivered so that people with palliative care needs, regardless of diagnosis, are supported to die in their place of choice.

The programme is based on whole system thinking. Traditionally, improvements have concentrated on individual parts of the system, without reference to one another. Working in partnership with the NHS, voluntary sector, social services and other healthcare providers, the programme develops patient focused 24-hour service models that service local needs and have an impact on the whole patient pathway.

The first programme was established in Lincolnshire. Interventions to improve the patient pathway and support choice over place of death include:

- a) A Palliative Care Coordination Centre, providing a single port of call for booking home care for patients across the full range of service providers;
- b) A community based Rapid Response Team, providing twilight and out of hours rapid response nursing care for patients, their families and carers;
- c) Discharge Community Link Nurses, ensuring the proactive management of the process of discharge from hospital;
- d) A programme to provide ongoing training and education for staff; and
- e) Wider support for patients and carers.

By using a whole systems approach and introducing interventions which impact on the whole patient pathway, the programme has increased the number of patients supported to die at home and has decreased the number of emergency admissions to hospital in the areas where the interventions are in place.

The programme is also underway in Leeds, Tayside (Scotland), Barnet (North London) and South East London. Service models designed by the programme differ in each locality based on local needs, and include:

- Dedicated palliative care ambulance services;
- Provision of palliative care in care homes;
- Improving access to palliative care for ethnic minority communities; and
- Boosting respite for carers.

**Contact details:** Peter Crutchfield, Director of Research and Development, Marie Curie Cancer Care. Peter.Crutchfield@mariecurie.org.uk

3.46 Coordination has also been supported by the development of GP practice registers of people who are approaching the end of life. These registers help to ensure that care given by the multidisciplinary primary care team is well coordinated. The registers attract points with the Quality and Outcomes Framework (QOF). To gain QOF points, a system needs to be in place that alerts the out of hours service or duty doctor of people who wish to die at home. At present, however, information from these registers is not usually available beyond the relevant general practice, so cannot be accessed by, for example, out of hours or ambulance services.

3.47 It may be useful to create locality-wide registers for people approaching the end of life, as set out by the end of life care working group in *Healthcare for London: A Framework for Action* (July 2007). Entry would need to be based on agreed criteria and subject to consent of the individual concerned. Entry could have a number of advantages for a person. These could include:

- Access to a 24-hour telephone helpline for the person and their carers;
- Access to rapid response services in the community for nursing care and/or specialist palliative care; and
- Ensuring that a person's wishes regarding advance decisions, such as for resuscitation and expressed preferences about where they would prefer to die, are known to all relevant services.

### The use of information technology to enhance coordination

3.48 As explained above, people approaching the end of life frequently require care from a range of service providers, for example hospitals, GPs, district

nursing services, community palliative care teams, hospices, out of hours medical services and ambulance services. Lack of effective mechanisms for communicating up to date, sensitive information between providers can be a barrier to achieving the goals of this strategy. For instance, out of hours and emergency services may not be aware of a patient's condition and preferences for care. This can lead to unnecessary hospital admissions. Conversely, if a hospital is unable to communicate with all relevant community services, patients who wish to be discharged to die at home may be precluded from doing so.

3.49 Recent progress on information technology within the NHS means that communication of sensitive information between providers is already achievable. Further developments over the next few years will extend the range of services available. In particular:

- NHS mail provides a secure communication channel between clinicians. This service is available without charge to anyone as long as they are exchanging information about NHS patients. There are currently around 160,000 active users of NHS mail with around 4000 additional users a month. Six hospices are already using this service and it does not require connection to N3 (see below). NHS mail could be used to send care plans or discharge summaries to several recipients. Hospices could have a generic account for this purpose;
- N3, the secure national IT network for the NHS, is the largest network in Europe. All NHS Trusts and GP practices and around 20 hospices are linked to N3. More are planning to join in the next two years. N3 allows connected sites to exchange information, including digital images. There is a modest installation fee and monthly rental for connection to N3;
- The Summary Care Record (SCR) is a summary of a patient's detailed care record. The main purpose of the SCR is to support care in an unscheduled, or emergency situation, when a patient's full record may not be available. Healthcare professionals will be able to access the SCR through N3. Out of hours services will be amongst the first to be able to access the SCR. It will be available in the majority of all care settings by 2010. The SCR could be one of the vehicles for sharing end of life care plans and resuscitation decisions; and
- HealthSpace is a secure online personal health organiser. Anyone over the age of 16 in England can open a basic HealthSpace account. Access is via the internet and going forward will be signposted through the NHS Choices website. Those who have opened an advanced HealthSpace



account and are living in SCR Early Adopter areas can access their SCR where one has been created.

- 3.50 **Considerable progress on communication and coordination can be made immediately by ensuring that all relevant providers open an NHS mail account and make use of this facility to communicate relevant information to others involved in the care of their patients. Over the next one to two years, good PCTs will wish to ensure that all relevant end of life care service providers have access to N3 and thus to the Summary Care Record and to the benefits of direct access to laboratory data, imaging and other information.**
- 3.51 **As the systems develop we will work closely with NHS Connecting for Health (CFH) to ensure the functionality exists within the systems to deliver maximum benefits to those approaching the end of their life.**
- 3.52 **Good commissioners of end of life care will wish to ensure that effective mechanisms are in place to facilitate coordination of care, both within individual organisations and across organisational boundaries. These mechanisms might include:**
- **Establishing a locality-wide register for those approaching the end of life;**
  - **People and their carers having access to dedicated helplines, so that they are less likely to need to make an emergency call to ambulance services; and**
  - **Establishing a single point of access through which services are coordinated, based on models such as Marie Curie Cancer Care's Delivering Choice Programme.**

## Step 4: Delivery of high quality services in different settings

3.53 Delivery of high quality services constitutes the fourth step in the end of life care pathway. Individual patients and their families/carers may need access to a complex combination of different services, including:

Primary care services	Equipment
District nursing services	Occupational therapy
Personal social care services	Physiotherapy
Psychological support services	Day care
Acute medical services	Pharmacy
Specialist palliative care services	Financial advice
Out of hours services	Dietetics
Ambulance/transport services	Carer support services
Information services	Spiritual care
Respite care	Community and voluntary sector support, including volunteers
Speech and language therapy	Interpreter services

3.54 Services need to be provided across a number of different settings – hospital, community, care home, sheltered/extra care housing or hospice. On some occasions they will also be needed in other locations, such as prisons, hostels for the homeless and independent living homes for people with learning disabilities. Discussions and recommendations on these specific services and locations are given in chapter 4.

**Box 10: Resource package for people with learning disabilities**

Learning disabilities experts in Northumberland, Tyne and Wear have combined to produce a resource pack to help support people with a learning disability at the end of life.

The guide for staff and carers contains easily accessible and practical information about resources to improve the management of specific symptoms, including how the use of end of life tools can reduce unnecessary hospital admissions, ensuring coordinated working between different organisations and agencies and bereavement care. The guide has helped build the confidence of carers, particularly those who are family members, and those working in care homes.

Feedback has been very positive, with many saying the resource fills a previously unmet need.

The pack is available as a hard copy, on CD Rom and as a download.

**Contact details:** Dorothy Matthews, Macmillan Nurse for People with Learning Disabilities. Dorothy.Matthews@nap.nhs.uk  
Claud Regnard, Consultant in Palliative Medicine.  
ClaudRegnard@stoswaldsuk.org (www.disdat.co.uk).

- 3.55 Whilst technically not a service, continued access to local community support, such as contact with neighbours, membership of social clubs and societies and local church or faith communities, will also be important. See chapter 2.

### Step 5: Care in the last days of life

- 3.56 How we care for the dying must surely be an indicator of how we care for all sick and vulnerable people. It is therefore paramount that care of the dying is recognised as a core activity with the same rigorous measures and outcomes as applied to other areas of health and social care.
- 3.57 How people die will remain in the lasting memory of relatives, carers, health and social care staff and so it is important that staff recognise their responsibility to provide the best possible care at the end of life.
- 3.58 A point comes in the care pathway when the person enters the dying phase. Identifying that a person is dying is potentially challenging but, in the context

of a deteriorating or progressive life-limiting illness and in the absence of any potentially reversible factors, various signs will suggest that a person may be in the last days, or hours, of life. They may become more withdrawn and slip in and out of consciousness, and they are likely to stop taking food and only take small amounts of fluid, if any. It is vital that those caring for them should recognise that such a person is dying and that appropriate action is taken.

- 3.59 This may be even more challenging in the acute care setting where staff inevitably focus on trying to ensure that the person survives. The availability of intensive care and organ support may make it harder to accept that the person is dying. In this context it is important that staff are aware of the person's preferences and whether any advance decision to refuse treatment has been made, or if the person has appointed an attorney. Wherever possible, relatives and carers should be involved in discussions about whether or not to intensify, or to withdraw, life-sustaining treatment and, if the person lacks capacity, then decisions must be made in their best interests and the family must be consulted as part of the process. In this context, death may occur rapidly and it is essential that families are involved in order to gain their acceptance and understanding.
- 3.60 Do Not Attempt Resuscitation (DNAR) decisions are an important element of care, which may be elicited through advance discussions with people about their wishes and preferences for future care and treatment. Since 2001, hospital Trusts have been required to have resuscitation policies in place to support people's choices about care.
- 3.61 Policies across Trusts may not always be consistent. This can have implications for ambulance services that may serve several Trusts. This can impact, for example, on how DNAR decisions are implemented when people are transferred between hospitals, to other service providers, or to their homes.
- 3.62 Representative bodies for service providers, including ambulance Trusts, care homes and hospital Trusts, may wish to explore how they can work together to put resuscitation policies into practice that best meet patients' needs, following the revision of existing guidance by the British Medical Association (BMA), the Royal College of Nursing (RCN), and the Resuscitation Council (UK).
- 3.63 Over the past few years a lot of work has been undertaken to ensure that all patients and their relatives and carers receive a high standard of care in the last days and hours of their lives. One approach which has been adopted to address this is the Liverpool Care Pathway for the Dying Patient (LCP). This was developed by the specialist palliative care team at the Royal Liverpool &

Broadgreen University Hospitals NHS Trust and the Marie Curie Cancer Care Hospice in Liverpool and has been underpinned by support from Marie Curie Cancer Care.

3.64 Although originally developed for the care of cancer patients in acute hospital settings, the LCP has been successfully implemented in hospices and care homes and has been modified to be used for people with other conditions, for example renal disease and heart failure. The LCP provides guidance on different aspects of care including:

- Comfort measures;
- Anticipatory prescribing of medicines;
- Discontinuation of inappropriate interventions, such as DNAR, and reviewing treatment regimes;
- Psychological and spiritual care; and
- Care of the family (both before and after the death of the patient).

3.65 Implementation of the LCP in a new setting involves a number of key steps:

- Training of health and social care professionals;
- Baseline reviews and analysis;
- Implementation and reflective practice; and
- Audit and evaluation.

### **Box 11: Developing the Liverpool Care Pathway for the Dying Patient for those with heart failure**

The Marie Curie Cancer Care Palliative Care Institute, Liverpool, is adapting the Liverpool Care Pathway (LCP) for use with heart failure patients who are dying. An expert panel of healthcare professionals and national organisations, representing palliative care, cardiac care and patient groups, has amended the current LCP to incorporate end of life issues pertinent to patients with heart failure and to devise appropriate information leaflets for patients, relatives and generic healthcare professionals to support the use of the pathway. The revised LCP has been implemented in ten hospitals using a locally appropriate education and training programme. The eventual aim is to roll it out to all hospitals. A wider assessment of the views of staff using the LCP in heart failure will also be carried out in each of the pilot sites using an adapted, standardised questionnaire.

Final amendments will be made to the LCP in heart failure prior to its wider roll out for use by patients with heart failure.

**Contact details:** [lcp.enquiries@rlbuht.nhs.uk](mailto:lcp.enquiries@rlbuht.nhs.uk)

- 3.66 **Good PCTs will want to ensure that the particular needs and wishes of all people who are dying should be identified and addressed. The LCP provides a well established mechanism for achieving this. PCTs are therefore strongly recommended to ensure that the LCP is adopted and its use audited in all locations where people are likely to die.**
- 3.67 **To enable people's choices to be respected and acted upon, all services dealing with people at the end of life should have resuscitation policies in place. Across a locality, attention should be given to ensuring that these policies are compatible, especially with regard to DNAR decisions.**

## **Step 6: Care after death**

- 3.68 Good end of life care does not stop at the point of death. When a person dies, all staff need to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes and cultural or religious and spiritual needs. Clinical staff should also be familiar with the role of the coroner and be able to form a judgement as to whether the coroner needs to become involved in a particular case. The way that this is carried

out, and the support and care provided to carers and relatives, will help them cope with their loss and is essential to achieving a 'good death'. Therefore, it is important that all staff who care for people who are dying and after death, are appropriately trained and supported.

- 3.69 However, currently there are a number of issues which are inhibiting good care after death. These are set out below.

### **Verification of death**

- 3.70 A key element of a 'good death' is the timely verification and certification of death. Whilst generally being responsible for completing both tasks, it is only in the case of certification of death that a doctor is legally required to complete the documentation; verification can, under certain circumstances, be performed by other clinically trained staff.
- 3.71 Problems do sometimes arise in primary care outside normal working hours, as some GP out of hours providers are unwilling to go out to a person's house to verify that a death has taken place. This can be distressing for families and carers, as funeral directors are unable to remove the body until the death has been verified other than for a coroner's post-mortem examination.
- 3.72 These difficulties have been addressed in some areas through the development of locally agreed policies to allow nurses to verify that death has taken place. These policies apply in cases where a person had a previously diagnosed chronic condition which had entered the terminal phase.

### **Box 12: Development of a Nurse Verification of Death policy across four PCTs in Hull and East Riding**

In response to an increasing amount of anecdotal evidence that carers were being forced to wait unacceptable amounts of time for a doctor to verify the death, particularly out of normal working hours, it was proposed that a policy be developed allowing nurses to perform this function.

A group of stakeholders, including the coroner's office, the police, the PCT Clinical Governance Department and the National Association of Funeral Directors, were brought together to consider the viability of this proposal and how it might be taken forward.

The resulting policy established a formal training programme covering a range of medical, legal and practical requirements, including:

- Practical training to correctly verify death;
- Procedures for dealing with expected, unexpected, suspicious and unexplained death;
- Supporting the bereaved and providing information for carers and relatives; and
- When and how to contact the funeral director, police and the coroner.

Nursing staff now play an important role in the verification of death process, with consequent benefits to carers and families who, in cases where the death is expected, no longer have to cope with the distress of long delays.

**Contact details:** Sue Pender, Integrated Team Leader, Westbourne NHS Centre. [sue.pender@hullpct.nhs.uk](mailto:sue.pender@hullpct.nhs.uk)

## **Certification of death**

3.73 The out of hours GP may be unable to certify a death if the death does not comply with existing legal requirements. To certify a death, a medical practitioner must have attended the deceased during their last illness (which is rarely the case for GP out of hours providers). However, even when a death has been certified, unless the doctor has seen the deceased in the 14 days preceding death, or viewed the body after death, the registrar is statutorily required to report the death to the coroner. Where a death cannot be certified, it must be referred to the coroner. It will in many cases be possible



for the patient's own GP to certify the death on the following day, but this may mean that the body of the deceased remains at the place of residence for several hours. Staff will need to explain this to the family as necessary.

- 3.74 The Department of Health has recently undertaken a public consultation on proposed changes to the process of death certification in England and Wales *Consultation on Improving the Process of Death Certification, 2007* ([www.dh.gov.uk](http://www.dh.gov.uk)). This consultation takes into account the issues outlined above.
- 3.75 In cases where out of hours GPs are unwilling and/or unable to verify and certify the death, it can become the responsibility of the police to attend the place of death. This can be a further source of distress to the family and carers, as the police may need to treat the place of death as a crime scene. Furthermore, outside normal working hours it is unlikely that any coroner's officers will be available to provide advice and support on best practice policies and procedures to the police and other professionals. However, coroners are available at all times to deal with inquests and post-mortems and unusual or complex cases should be referred for further advice via the police as necessary. Cases should not be referred to the coroner, or his office, solely because there is no one available for several hours to verify or certify death.
- 3.76 Referrals to coroners are necessary in some cases. For example, if the death was violent, unnatural or suspicious, if it occurred in custody, or if the cause of death is unknown. In cases where this is likely to be the case, families and carers should be alerted to prevent undue distress and enable them to make appropriate preparations.
- 3.77 However, in many cases deaths are reported to the coroner where it may be avoidable. This can create inconvenience and distress to families, as referrals to the coroner may delay any funeral arrangements and may involve post-mortem examinations. In both instances, this runs counter to the beliefs and practices of some faiths.
- 3.78 The majority of deaths are referred to coroners by doctors yet there is no current statutory requirement for them to make referrals and neither is there a nationally recognised list of the particular types of death they should refer. Although many coroners issue guidance to medical professionals in their areas, there is no standard practice, and a case which may be referred to a coroner in one area is not necessarily referred in another area. In practice, this means that coroners have deaths referred to them which should not have been and, to a lesser extent but more worryingly, vice versa.

3.79 At present:

- Around 47% of all deaths are reported to the coroner. This figure has increased significantly since 1990 (32%);
- Around 22% of all deaths are followed by a post-mortem; and
- Around 6% of deaths are followed by an inquest (most having undergone a post-mortem).

3.80 To address these challenges, the Ministry of Justice (MOJ) consulted on proposals on whom the duty to report deaths should rest, the circumstances and categories of deaths that should be reported to the coroner, and possible sanctions that may apply if there is a failure to report a relevant death to the coroner in the consultation paper *Statutory Duty for Doctors and other Public Service Personnel to Report Deaths to the Coroner*. A summary of the responses to the consultation paper was published on 21 May 2007. A statutory duty to report deaths to coroners will be introduced through the Coroners and Death Certification Bill, and will be placed on registered medical practitioners only, although it will not prevent anyone else from being able to report a death, including family members, if they have concerns.

3.81 Ahead of legislation, the MOJ intends to work across Government and with those who work in the coroners' service to produce national guidance for England and Wales to clarify which deaths should be reported to the coroner to take this policy forward. This national guidance will form the basis of the list of reportable deaths, and will be framed in secondary legislation and associated guidance under the Bill when it is implemented. The aim is that coroners have referred to them the cases they should be investigating, but do not have to devote resources to cases which do not fall within their jurisdiction.

3.82 The MOJ is also consulting on a Charter for Bereaved People. The charter describes the services bereaved people can expect to receive from a reformed coroner system.

## Organ donation

3.83 In some cases, there may be potential for organ donation to take place. An individual may have given their consent to the donation of their organs prior to death. A nominated representative, or someone in a qualifying relationship, might indicate that it is what the deceased would have wanted and provide their consent. Discussion concerning organ donation with the relatives of a potential organ donor must respect the cultural and religious beliefs of the individual and the family. Donor transplant coordinators

are specifically trained to do so and are the most appropriate healthcare professionals to undertake such discussions. Staff should be aware that, if the cause of death needs referral to the coroner, the coroner's views on organ donation should be sought in case the body is likely to be required for post-mortem examination. Details on the legal requirements and good practice relating to transplantation can be found in the Human Tissue Authority Code of Practice on the donation of organs, tissues and cells for transplantation ([www.hta.gov.uk](http://www.hta.gov.uk)). Information on the perspectives on organ donation of the six major religions in the UK and on specialist transplant centres can be found on the UK Transplant website ([www.uktransplant.org.uk](http://www.uktransplant.org.uk)).

**Box 13: Bolton Hospitals bereavement and donor support team**

Bolton Hospitals Trust's bereavement and donor support team offers support to relatives and staff in the immediate aftermath of a patient's death. The team ensures that all families are offered religious and spiritual support following bereavement and, as appropriate, the option of organ or tissue donation.

The service, which is jointly funded by Bolton Hospitals NHS Trust and UK Transplant, promotes best practice in bereavement care, modelling itself on the Department of Health's guidelines, *When a Patient Dies* and *Saving Lives, Valuing Donors* and the Human Tissue Act (2004).

At first, the team encountered some resistance to its work from staff who feared families' grief would be heightened if they were approached about donation. But in fact the opposite has happened, with organ or tissue donation being seen as a positive outcome from a tragic situation. A Trustwide link nurse system has helped give staff the confidence to approach newly bereaved families to establish the deceased's wishes.

Staff, patients and families now view organ donation as normal practice within the Trust.

**Contact details:** Bereavement & Donor Coordinator  
[Fiona.murphy@rbh.nhs.uk](mailto:Fiona.murphy@rbh.nhs.uk)

## Handling of the body

- 3.84 Where death occurs in an institution, once death has been verified the body needs to be handled and laid out in a culturally sensitive way and in keeping with any religious beliefs. Some people may wish to spend a long time with

the body. Staff should support these wishes, but should be aware and advise families of the implications this may have for later viewings of the body if refrigeration and embalming is delayed.

- 3.85 Staff need to be familiar with the arrangements for disposal of the body, particularly cremation where medical staff may be involved in the completion of the certification. Staff will also need to be aware that, for some religions and cultures, the practice of cremation is undesirable and alternative arrangements for the disposal of the body, such as burial, may need to be considered in discussion with the deceased's family or friends.

**Box 14: Care of the deceased: multidisciplinary guidelines**

The Royal Free Hampstead NHS Trust has produced new multidisciplinary guidelines to improve care immediately after death and ensure relatives receive appropriate, timely information following their bereavement.

A comprehensive teaching plan has been instigated for all professionals and is now a standard part of all induction programmes for doctors and nurses.

An efficient and responsive bereavement service is seen as integral to the development of the Trust's end of life strategy. Initially managed by support services, the bereavement office is now overseen by the Macmillan nurse consultant in palliative care, which provides a more clinically focused structure.

**Contact details:** [katherine.hopkins@royalfree.nhs.uk](mailto:katherine.hopkins@royalfree.nhs.uk)

## Communication between professionals

- 3.86 Staff should also alert other staff involved in someone's care to the death and to update their records. If this is not done, the carers and family may continue to receive correspondence for the deceased in relation to, for example, reminders about appointments, which they can find very distressing.
- 3.87 **Policies which ensure timely verification of death should be agreed and put in place by all PCTs. This may include verification by nurses.**
- 3.88 **Comprehensive training on death certification should be included in pre and post-registration training curricula. Supporting the training of junior doctors in death certification, and providing feedback on**

**accuracy of certification locally should also form part of the 'medical examiner' role, envisaged as part of the Department of Health's proposed changes to the process of death certification.**

- 3.89 **Organisations caring for people at the end of life should have policies in place to ensure that care after death is sensitive and responsive to the cultural and spiritual needs of the deceased and their families.**
- 3.90 **Organisations providing end of life care should have processes in place to ensure that the bodies of the deceased are correctly identified and that personal possessions are handled in a safe and sensitive way.**
- 3.91 **Organisations which have adopted the LCP should consider using the care after death module for all deaths, including sudden death.**
- 3.92 **Good PCTs and LAs will wish to ensure that the mortuary facilities for which they are responsible maintain high standards and meet the needs of relatives and carers who wish to view the body.**

### **Information for patients and carers**

- 3.93 For those approaching the end of life and for their carers, friends and families, it is important to access reliable sources of information as quickly as possible. Gaining access to information that is understandable and appropriate to the individual situation can reduce anxiety and enable and empower people to cope more effectively. Often, it is when people do not understand and have little information that they feel the most powerless and vulnerable. Currently, there is no one 'basket' from which all information on end of life care can be accessed. People have to search through numerous information sources, modes and formats in order to find out information about their particular condition, what to expect, what services might be available to them and where they could go for practical and emotional support. This in itself creates further anxiety and stress.
- 3.94 Ideally, people need a 'one-stop shop' where they can access information on a variety of subjects and issues such as:
- Condition specific support;
  - Financial support and benefits;
  - Employment support;
  - Support that is available to both patient and carer;

- Practical advice on what to do when someone dies; and
- Bereavement support

- 3.95 In order to address these issues, Marie Curie Cancer Care and the newly constituted National End of Life Care Programme (see chapter 8) are undertaking a joint mapping exercise. This will identify what materials and support currently exist and gaps in provision. It will identify models of good practice locally, nationally and internationally across the wider health and social care arena for all conditions.
- 3.96 Building on this work, Marie Curie Cancer Care is exploring how the need for information, advice and support can best be met for patients, carers, families and friends affected by a terminal diagnosis. This in turn will help to establish the best form of 'access' to services so that patients, carers and families know where and how to find the relevant information.
- 3.97 **Good PCTs, working in partnership with LAs, will wish to ensure that information is readily available on all local services, which will support those approaching the end of life and the bereaved, including: community support, funeral directors, social and health services, Citizens Advice and the voluntary sector. This might include a directory of local services.**

### Spiritual care services

- 3.98 This section deals with the recognition that each person has spiritual, religious or emotional needs. This may, or may not, mean that they have a strong faith, belong to a particular faith community or hold to a religious or non-religious belief system.

- 3.99 Facing death and the associated pain of loss and separation is hard to bear for all those concerned. Each person is part of a family or community unit and has emotional, social and spiritual needs, as well as physical and practical needs. Every person is unique and should be treated with dignity and respect. They should be able to express their hopes and expectations of what has deepest meaning for them. In essence, this is a recognition of the spiritual dimension of each person.
- 3.100 Many people need to discover their own way of making sense out of what is happening to them. So allowing the person to express anger, guilt, sadness and reconciliation is an important aspect of caring. It is important that spirituality is part of the assessment process, so that it becomes an integral part of care and is reviewed at each stage of the pathway.
- 3.101 Some organisations, such as hospitals and hospices, provide chaplaincy services to ensure that inpatients, carers, families and staff have access to spiritual care. At a workshop on spiritual care to support the development of the strategy, representatives recognised the important role of chaplains and endorsed the term 'chaplaincy services' as an acceptably inclusive term for a service that caters to all faiths and spiritual needs. To enable chaplains to provide the required support, it is essential that they are recognised as a core member of the multidisciplinary team.
- 3.102 The provisions of the Data Protection Act 1998 mean that organisations must not disclose information about a patient's religious affiliation to chaplains for the purposes of spiritual care, without first obtaining that patient's consent. Organisations should make every effort to find out information about patients' religious affiliation on, or prior to, admission and ensure that this is recorded. At this stage, they should also seek the patient's consent for that information to be conveyed to the appropriate chaplaincy service. This is helpfully set out in guidance on the provision of spiritual care, *NHS Chaplaincy: meeting the religious and spiritual needs of patients and staff* (DH, 2003.)
- 3.103 Although consultation indicated there are few, if any, issues of principle dividing the faiths in care of the dying, nevertheless the individuality of the person and their faith (or no faith) should be recognised. There are, however, specific variations in practice between faiths and these should be understood and accommodated. Those caring for the dying and bereaved should have a reasonable knowledge of various practices of different faith groups, know the limits of their knowledge and, where necessary, seek help and support.

- 3.104 For those approaching the end of life there is often a need and desire for ritual actions in relation to death and bereavement. This often extends to those who would not normally describe themselves as religious or spiritual. For those who are bereaved (including carers, families and staff), there is also a need to provide occasions and rituals for remembrance.
- 3.105 It should be noted, however, that no matter how skilled a chaplain may be at ministering to a wide range of people, including those without faith, there will be some who will only be able to accept the ministry of an accredited minister of their own faith or church. Healthcare chaplains will have links with local faith and community groups and can help to facilitate this.

**Box 15: Addressing the spiritual needs of individuals nearing the end of life**

St Michael's Hospice in Hereford has identified that the spiritual needs of those at the end of life are not always recognised or assessed appropriately. This may be because of the close association with religion and therefore not recognising that all individuals, with or without faith, may have spiritual needs related to regret, meaning, value and purpose. In response to this, an assessment tool has been developed which includes open questions about support and beliefs systems and the impact of the illness on these.

Once the beliefs, concerns or worries have been identified for both the individual and their carers, appropriate support is offered. This is provided by trained volunteers in the spiritual care team who provide support to patients and families, which includes helping them to reconcile their beliefs and help with putting their affairs in order and assistance with funeral arrangements.

To assist in overcoming staff concerns, information is available which lays out clearly rituals around death and ensuring that these are respected.

**Contact details:** david.vonberg@st-michaels-hospice.org.uk

- 3.106 **An assessment of spiritual needs, which is reviewed regularly, should be part of all patient and carer assessments.**
- 3.107 **Spiritual, religious and cultural care competences should be adopted within all core training.**



- 3.108 **Occasions of remembrance should be organised to help and support bereaved people. At these events, information about bereavement support should be available and further opportunities provided for people to self refer to bereavement services.**
- 3.109 **In order for chaplains to be able to work effectively as part of the multidisciplinary team, organisations should be mindful of the Information Commissioner’s definitive ruling about chaplains accessing patient information and put in place robust systems to ensure consent is obtained and recorded on, or prior to, the patient’s admission.**

# Chapter 4: Care in different settings

## Introduction

4.1 People approaching the end of life require care in a variety of different settings. This chapter sets out the actions which need to be taken to ensure the provision of high quality care in:

- Acute hospitals;
- The community (mainly in a person's home);
- Care homes and sheltered and extra care housing;
- Hospices;
- Community hospitals;
- Ambulance services;
- Prisons and secure hospitals; and
- Hostels for the homeless.

## Improving the environment

4.2 The physical environment of different settings, including hospitals and care homes, can have a direct impact on the experience of care for people at the end of life and on the memories of their carers and families. Central to this is the importance of providing settings in which dignity and respect are facilitated. Work carried out by the King's Fund (*Enhancing the Healing Environment*) echoes these messages and highlights a number of key environments and environmental issues which affect the quality of end of life care. These are particularly important during the last days of life and following death.

4.3 The areas highlighted by the King's Fund include:

- A room where the person and their family can go to talk privately;
- Informal 'gathering' spaces where family and friends can meet to confer and talk with staff; and
- Guest rooms where close family and friends can stay overnight, with facilities for catering and communication.

Following the death, particular attention needs to be given to:

- The transfer of the body to the mortuary;
- The location of the mortuary and how it is approached by family, friends and carers;
- Rooms where the body is viewed by family, friends and carers; and
- Rooms where family, friends and carers can sit quietly and receive the deceased person's property and collect the death certificate.

Enhancing the Healing Environment [www.kingsfund.org.uk](http://www.kingsfund.org.uk)

- 4.4 **Good providers will wish to assess the quality of the environment from the perspective of people at the end of their lives and their carers and will wish to incorporate any plans for change into their formal estates strategies. Commissioners will wish to consider whether the environments are adequate, or whether enhanced, or new facilities, are required.**

## Acute hospitals

- 4.5 At present over half (58%) of all deaths occur in acute hospitals. An even larger proportion of patients who die in any one year will have had at least one admission to an acute hospital in the year before death.
- 4.6 Although one of the key aims of this strategy is to enable more people to be able to die in the place of their choice and thus to reduce the number of hospital deaths, hospitals will almost certainly continue to be the most common place of death in this country for the foreseeable future. It is therefore imperative that actions should be taken to improve the quality of end of life care which they provide.
- 4.7 Several observational studies have shown that a proportion of patients dying in hospital experience very poor care. They may not receive optimal symptom control, communication may be poor and patient and family involvement in end of life decision making may be lacking. Their carers may receive insufficient information and support and may not be enabled to participate in the provision of care to the extent that they would wish. These problems with care are reflected in the high number of complaints from bereaved relatives identified by the Healthcare Commission as being related in some way to care of the dying.

- 4.8 The problems identified in acute hospitals are likely to relate to:
- A failure to recognise that one of the core roles of an acute hospital is to provide care for the dying;
  - A failure to recognise when continuation of treatment is not in the best interest of the person, resulting in a failure to address their holistic needs;
  - A failure to take responsibility for enabling people to return home to die if that is their wish;
  - A lack of leadership on end of life care from senior managers and senior clinicians; and
  - Staff at all levels not having the necessary knowledge, skills and attitudes required to deliver high quality end of life care.

**Box 16: The Rapid Discharge Pathway for the Dying Patient**

The Rapid Discharge Pathway for the Dying Patient has been developed by Marie Curie Cancer Care Palliative Care Institute, Liverpool.

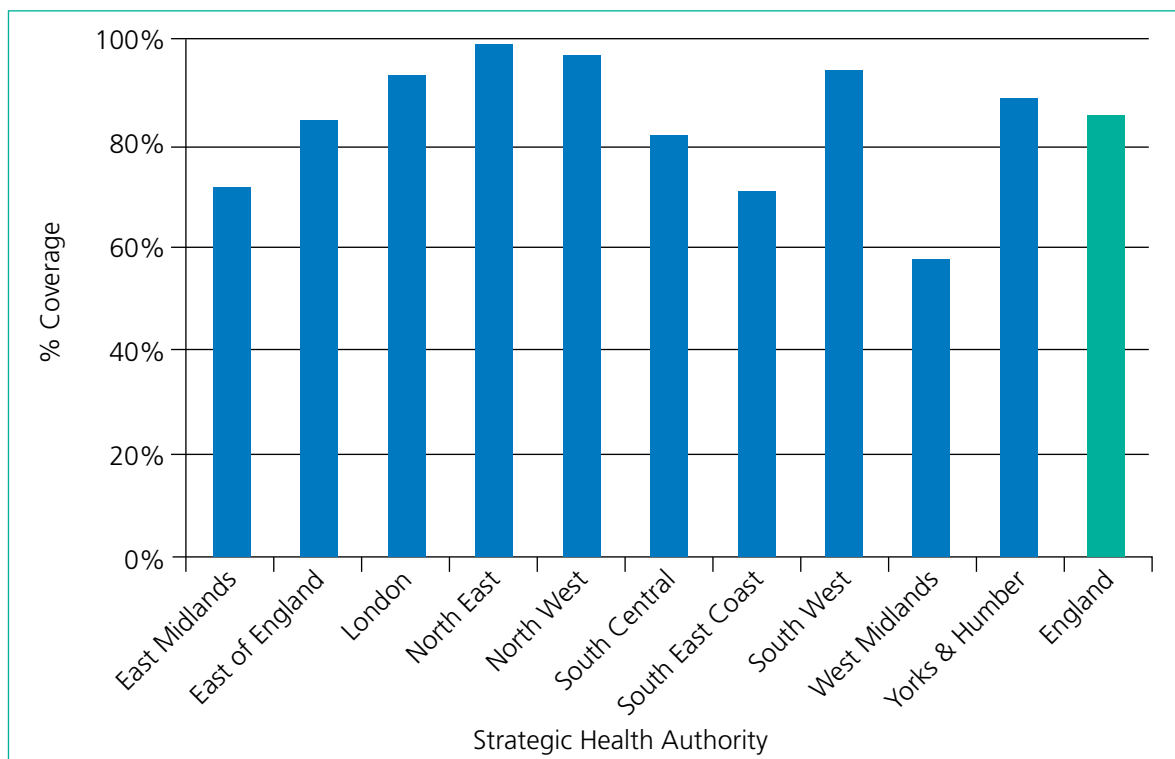
This supports coordinated care, to enable patients, where possible, to be discharged from the acute hospital to home in the last hours/days of life, if this is what the patient wants. This model of care provision can be adapted by other organisations as part of a continuous quality improvement programme for care of the dying.

**Contact details:** [Deborah.murphy@rlbuht.nhs.uk](mailto:Deborah.murphy@rlbuht.nhs.uk)

- 4.9 Against this there is sound evidence that the quality of care in acute hospitals can be improved by establishing a specialist palliative care team. There is also accumulating evidence that care provided by staff who are not specialists in palliative care can be enhanced by training.
- 4.10 **The Boards of Primary Care Trusts (PCTs) and NHS Trusts should prioritise their resource allocations to ensure that adequate resources are made available both for specialist palliative care services and for improving the quality of care provided by other health and social care professionals involved in end of life care. Boards will wish to formally review progress on improving end of life care in acute hospitals at least once a year.**

**4.11 To improve end of life care, commissioners and providers will wish to ensure that all acute hospitals have:**

- **An appropriately constituted specialist palliative care team (as set out in the *NICE Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer (2004)*). This team should, however, provide care based on patients' needs rather than being limited to any specific diagnoses;**
- **Mechanisms to ensure that people who may be approaching the end of life, or who are at substantial risk of dying on admission to hospital, are identified;**
- **Mechanisms to ensure that relevant healthcare professionals have the necessary competences to initiate discussions regarding end of life and to elicit priorities and preferences and to meet physical, psychological, social and spiritual end of life care needs;**
- **Mechanisms to ensure that people who are approaching the end of life have their needs assessed and are offered a care plan;**
- **Mechanisms to 'fast track' assessments for NHS Continuing Care, so that decisions can be made quickly and services put in place to enable people to leave hospital and die elsewhere, including their own home if that is their wish;**
- **A framework to ensure the delivery of appropriate care for people who are in the dying phase of their illness and after death. The Liverpool Care Pathway for the Dying (LCP) is an example of such a framework; and**
- **Mechanisms for monitoring the demographics (including race, gender, age, religion/belief, disability and sexual orientation) of patients dying in hospital and the quality of care delivered.**

**Figure 4: Uptake of the Liverpool Care Pathway: NHS Acute Trusts**

Note: Uptake of the Liverpool Care Pathway indicates that LCP has been implemented on at least three wards in an acute Trust. Across England as a whole, this has been achieved in over 80% of Trusts. However, only 17% of Trusts have introduced LCP to all appropriate wards.

## The community

- 4.12 Most people will spend the large majority of their last year of life in the community. More could do so through a reduction in avoidable admissions to hospital.
- 4.13 People may require a diverse range of health and social care services to enable them to continue living at home and to die there if that is their wish. These include primary care, district nursing, domiciliary, social care, community pharmacy, occupational therapy, physiotherapy, dietetics and out of hours services. Support for carers may also be essential if they are to continue providing direct support to a patient.
- 4.14 General practitioners have a pivotal role in the provision of end of life care and care for the bereaved. Approximately 1% of the population die in any one year. A GP with a list of 1700 patients can therefore expect around 17 of their patients to die each year. However, they are likely to have contact with a considerably larger number of patients approaching the end of life, as they

provide cross-cover for their partners and if they provide out of hours care. The people they care for will be at home or in care homes. As these locations account for around 35% of all deaths, a GP might be expected to manage six or seven patients in the dying phase of their illness each year.

- 4.15 Care for people approaching the end of life represents a considerable proportion of the workload of most community nurses. The Audit Commission study (1999)<sup>3</sup> demonstrated that palliative and terminal care patients took up to 40% of a district nurse's time, but only 8% of their caseload. In response, the Department of Health funded a £6m three year programme (2001 to 2004) to train district nurses in the principles and practice of palliative care. The programme reached over 15,000 district nurses and other healthcare professionals. However, it is recognised that there are still many community nurses who have received little or no post-registration education in this area.
- 4.16 The major challenges in relation to the delivery of high quality end of life care in the community include:
- Poor identification, assessment and coordination of end of life care within some general practices;
  - Lack of availability of nursing services and personal care services on a 24/7 basis in some parts of the country;
  - Poor access to prompt provision of equipment and modifications to a person's home;
  - Difficulty in accessing medicines outside routine working hours;
  - Lack of training and continuing professional development for some key staff groups;
  - Poor coordination between service providers in primary and secondary care and especially between daytime and out of hours services; and
  - Inadequate information to carers about what to expect, and what to do.
- 4.17 These deficiencies in services can have a severe adverse impact on the wellbeing of patients and carers. There is increasing evidence that the lack of well coordinated community based care leads to avoidable admissions and to prolonged hospital stays. However, there is also increasing evidence that these deficiencies in care can be rectified through the introduction of innovative service models and approaches to practice.

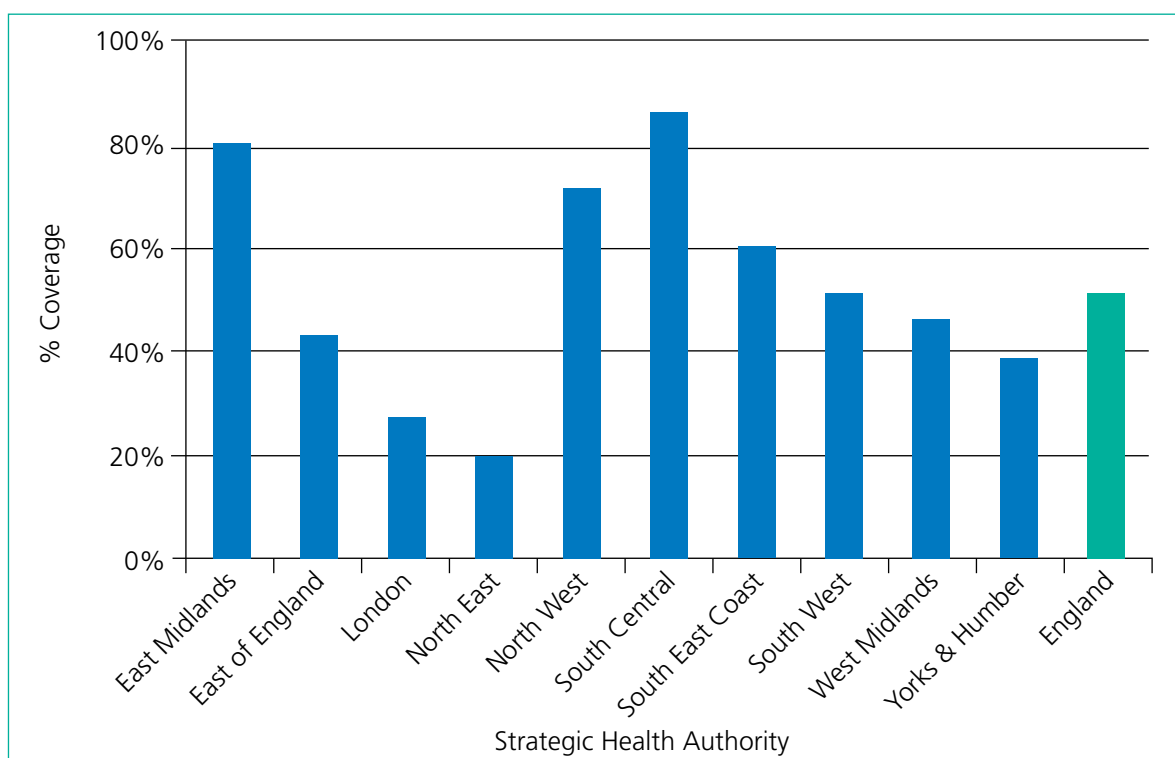
3 *First assessments: a review of district nurse services in England and Wales*. Audit Commission, London (1999)

## The Gold Standards Framework

- 4.18 This approach is designed to care for people with advanced, progressive, incurable illness, mainly in the primary care setting. It enables GPs to identify patients for inclusion on the palliative care register, which attracts Quality and Outcomes Framework (QOF) points. The approach helps primary care teams to work together in optimising continuity of care, teamwork, advance care planning, symptom control and patient, carer and staff support.
- 4.19 The QOF has an indicator set for palliative care. Originally linked with cancer care, this indicator is now providing the impetus to improve end of life care for all those with advanced disease. Each GP practice establishes a register of all those who require end of life care. The ongoing care of those on the register is regularly reviewed at multidisciplinary planning meetings. The creation of the register enables the wider practice team to provide more appropriate and patient focused care, such as reception staff being aware of the need to prioritise communication from relatives to clinical staff if the person is on the register.

**Figure 5: GSF Uptake/coverage: GP practices**

(Data source: NHS EOLC Programme Jan 2008)



Note: Uptake of the Gold Standards Framework (GSF) by a general practice does not necessarily indicate that all four levels of the framework have been fully implemented.



## Additional home care services

- 4.20 Several different models have been developed to provide individuals with the additional support they need to continue living at home if that is their wish. These include 'hospice at home' services and rapid response services, which enable patients to be assessed out of hours in their own homes and for services to be provided which otherwise might require a patient to be taken to an Accident and Emergency department.

### **Box 17: Fair Havens Hospice at Home working collaboratively with SPDNS Nurse Care**

In Essex, Fair Havens Hospice at Home and SPDNS Nurse Care (a Community Interest Company), working collaboratively with a broad range of services, including Fair Havens Hospice, primary care and social services, provide integrated nursing and social care to enable people at the end of life to be cared for, and die, in their own home.

The Hospice at Home service, which is based at SPDNS Nurse Care's offices, is provided by qualified nurses and nursing auxiliaries, who have received training in specialist and supportive palliative care. They provide both crisis intervention and planned respite care, usually for up to three months at home, to support carers and families in and to enable them to cope with their caring role. Hospice at Home is funded by voluntary donations administered by Fair Havens Hospice, carers grants from Local Authorities (LAs), and PCT and Marie Curie Cancer Care matched funding.

This crisis and respite care is well integrated with personal care for these patients, which, whilst funded by the LA, is provided by SPDNS Nurse Care, working closely with Hospice at Home nurses.

The collaborative service aims to avoid the unnecessary admission of patients to the hospital, or hospice, through the availability of 24/7 access to specialist palliative care advice and support for staff, patients and carers. This is enhanced by the provision of a rapid response service, whereby a Hospice at Home Clinical Nurse Specialist will visit the patient's home to provide crisis intervention within one to two hours, where needed.

**Contact details:** Rosalind Matty, SPDNS Nurse Care Director  
rosalindmatty@spdnsnursecare.co.uk

### **Box 18: Marie Curie Cancer Care Lincolnshire Rapid Response Team**

One of the elements of the Marie Curie Cancer Care Delivering Choice Programme in Lincolnshire is the Rapid Response Team (RRT).

The unavailability of 24 hour planned cover for patients and carers was identified as a major barrier to provision of home care. RRT provides twilight and out of hours nursing care for patients with palliative care needs, their families and carers at home. Team members make planned and emergency visits as well as provide support and advice over the phone. The team also liaises with other care providers, out of hours teams and the Palliative Care Coordination Centre to ensure an integrated service, provide specialist night support where night care is unavailable, and maintain and transfer patient information as appropriate.

Between July 2006 and July 2007, 770 patients received services from the RRT. During this period there were 2259 calls to the service, 66% of which were for planned and urgent home visits and the remainder of which were telephone advice and support. Five hundred and twenty two admissions via A&E were prevented.

Forty seven per cent of all calls to the service were from patients and carers. Common reasons for calling the RRT included calls for physical symptom control (51%), for psychological reasons (25%) and for social reasons (11%); the remaining 13% of calls included covering unmet need in the county, or for medication advice.

*'Having the rapid response team come was like someone throwing a lifebelt.'* – Carer

The team provides the service seven days per week during the twilight and out of hours period and is staffed by one full time team manager, four full time registered nurses and four full time healthcare assistants. The costs of running the team are met by Marie Curie Cancer Care.

**Contact details:** Peter Crutchfield, Director of Service Modernisation,  
Marie Curie Cancer Care  
Peter.Crutchfield@mariecurie.org.uk

## Out of hours services

- 4.21 It is clear that there are special problems in respect of those requiring end of life care in the community being able to access urgent care, including medicines, outside 'normal' NHS hours. There is inequity of access and widespread difficulty in accessing a full range of services, often resulting in delays in providing appropriate care.
- 4.22 Primary care out of hours (OOH) services in the community operate as an extension to regular daytime general practice led care. When well planned and organised, they can play a critical role outside 'normal' NHS working hours, ensuring the identified needs and expressed preferences for care for people at the end of life are carried out. In this context, improving access to appropriate training for clinicians working in OOH services can reduce calls to the ambulance service as the 'safe' course of action and reduce unnecessary admissions to hospital, enabling individuals to remain at home.
- 4.23 The condition of those reaching the end of life can change rapidly, thereby requiring an urgent response. Adequate and timely provision of services and medicines is vitally important in the provision of high quality care at the end of life. Improvements can be made in a number of ways, such as:
- OOH providers having access to the most up-to-date information about vulnerable patients, their needs and wants in their service database;
  - Proper protocols to ensure that when these patients, or their carers call, they are not required to go through the normal routine assessment of needs, but are immediately put through to a clinician who can respond quickly and effectively to their needs;
  - Access to medicines advice through effective commissioning of community pharmacy services;
  - Effective anticipatory planning of the need for prompt access to additional medicines, for example, the use of anticipatory prescribing and palliative care 'Just in Case' boxes stored at the patient's home;
  - Total clarity for patients and their carers about which telephone number to call in the OOH period, which could be accomplished through a dedicated telephone line for people on the register; and
  - Training in end of life care for those staff who are working for OOH services.

- 4.24 Guidance on the supply of and access to medicines, particularly controlled drugs, to those people who choose to die at home, is available in *Securing Proper Access to Medicines in the Out of Hours Period – a Practical Guide for PCTs and Organised Providers* (DH, 2004). Community Pharmacists can provide additional support to people in their homes by delivering medicines, answering questions and providing advice. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4134235](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134235).

**Box 19: Hampshire initiative – out of hours (OOHs) service**

In Hampshire, a collaborative approach by the OOH service, the ambulance service and the Gold Standards Framework Facilitators has significantly improved care in the OOH period. All the general practices complete a form which holds comprehensive details of the patient (their diagnosis, treatment plans and medication) and patients explicitly consent to sharing this data with the ambulance and OOH service. Once the form is completed, it is faxed through to the Emergency Operations Centre, where details are stored on both the OOH and the ambulance computer systems.

The result is that if a patient, or their carer, calls either the ambulance or OOH service, they bypass the routine assessment and are put through to a nurse who has access to up-to-date information about the patient and can arrange an appropriate response. Clinicians from the OOH, or ambulance service, can also access advice from a consultant in palliative care based at a local hospice and specialist equipment can be made available through the district nursing service. This initiative has already seen significant improvements in care – an audit of 50 random cases between November 2006 and April 2007 found that of those patients who wanted to die at home, 72% did in fact die at home.

**Contact details:** Paul Anfield, Head of Unscheduled Care, South Central Ambulance Service. [Paul.Anfield@nhs.net](mailto:Paul.Anfield@nhs.net)

Alison Kidman, District Nurse/Senior Sister & Gold Standard Facilitator, Southampton City PCT. [Alison.Kidman@nhs.net](mailto:Alison.Kidman@nhs.net)

- 4.25 **Good PCTs, working with LAs, will wish to ensure that:**

- **The range of services (medical, nursing and personal care) which people need to enable them to live and die at home are available, including those which are required 24/7. Particular attention should be given to ensuring that rapid response nursing services are available for people approaching the end of life in areas where full 24/7 community nursing services are not currently available;**

- **The services, including those provided by LAs and by the voluntary sector, work effectively together to deliver seamless care for patients and carers;**
- **An end of life care register is established which is accessible to all appropriate service providers, for example ambulance and OOH services;**
- **General practices have systems in place to identify, assess and plan for the care of people approaching the end of life. The GSF is an example of such a system;**
- **OOH providers have access to up-to-date information on the care needs and expressed preferences for care of all people who are approaching the end of life;**
- **OOH providers put in place protocols to ensure that people at the end of life who call the service are immediately identified and transferred to an appropriate clinician. This may be accomplished through the provision of a dedicated telephone line for people receiving end of life care who are also on the register; and**
- **All staff working in OOH services should receive training in end of life care.**

### Care homes and sheltered and extra care housing

- 4.26 In March 2007, there were a total of 18,577 registered adult care homes in England, offering a total of 441,958 places. Approximately 4048 of these homes are care homes with nursing and 14,515 are care homes providing personal care.
- 4.27 A significant proportion of the residents of care homes suffer from dementia. Recent research indicates that over 200,000 people with dementia live in care homes, which represents around one third of all people with dementia.
- 4.28 Many people enter a care home because they are no longer able to live independently in their own home. For these people the care home becomes their normal place of residence and many would choose to stay there until they die. Others enter a care home for respite care, or for nursing care and rehabilitation, with a view to returning to independent living.
- 4.29 At present around 80,000 people die in care homes each year, representing around 16% of all deaths. However, there is accumulating evidence that significant numbers of residents are being transferred from care homes to

acute hospitals in the last days, or weeks of life, when this is not necessarily their wish, or in their best interests.

4.30 Several different factors contribute to suboptimal end of life care being delivered in care homes, and sheltered and extra care housing,<sup>4</sup> which include:

- End of life care not being discussed with residents, with a consequent lack of advance care planning;
- Inadequate recognition of when end of life begins and a failure to undertake, or arrange for, an holistic assessment of needs and preferences;
- Concerns in some care homes that if too many residents die in the care home, this may reflect badly on the care being delivered – and might even lead to accusations of a ‘Shipman’ effect;
- Concerns about the impact on other residents of people dying within the care home, or in sheltered and extra care housing;
- Inadequate access to NHS services, for example, district nursing care, primary medical care, OOH medical care, community palliative care teams;
- Inadequate review and management of medicines; and
- Inadequate training of staff at all levels within the care home and sheltered and extra care housing sector. This is considered to be the single most important factor.

4.31 Over the past three years (2004 to 2007) significant new initiatives have been facilitated by the NHS End of Life Care Programme to improve the quality of end of life care in the care home sector. Over 1300 (7.6%) care homes are now involved in these initiatives around the country.

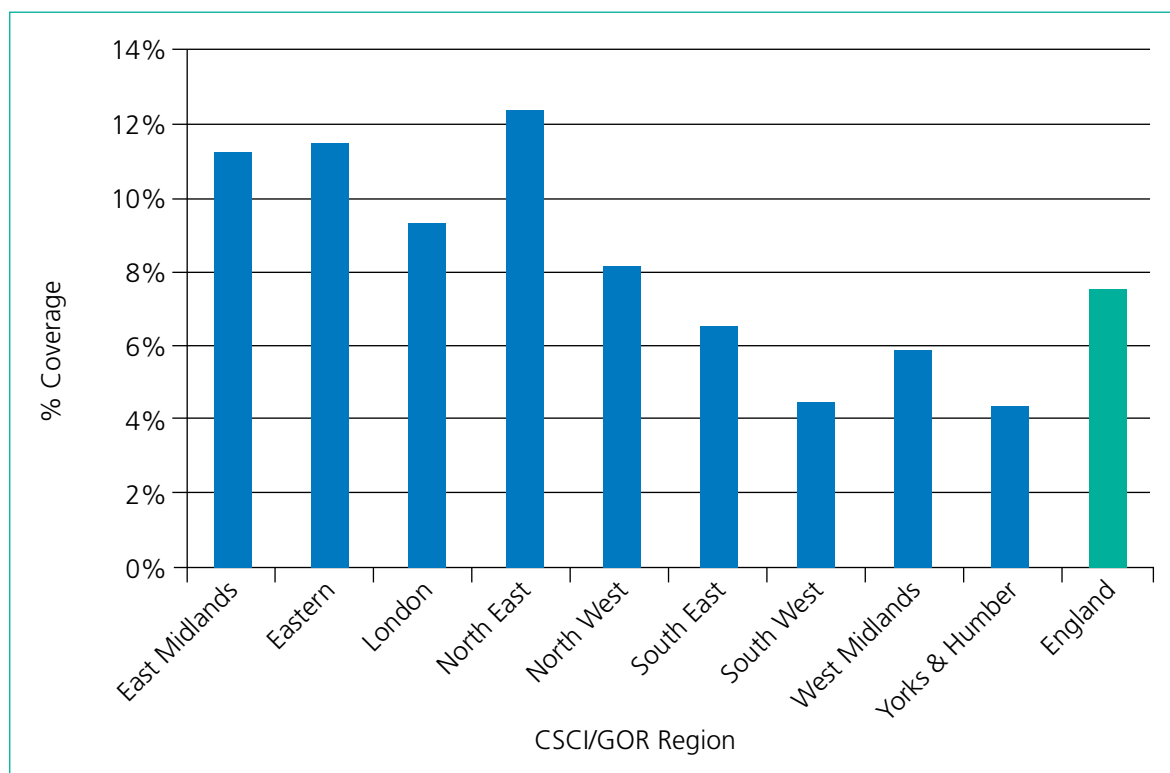
4.32 The approaches being adopted by the care homes reflect the different steps in the end of life care pathway set out in chapter 3, but also include specific support for carers and for other residents of the care home.

4.33 The NHS End of Life Care Programme has demonstrated that tools and approaches which were developed for use in other sectors can be modified for successful use in care homes. Approaches have also been developed from within the sector, such as those from the Anchor Trust, Methodist Homes Association Care Group and Heart of England Housing Care Limited. In addition, a number of approaches have been developed in collaboration with specialist palliative care providers.

4 Extra care housing is designed with the needs of frailer older people in mind with varying levels of care and support available on site.

**Figure 6: Uptake of the End of Life Care Tools: care homes**

(Data source: CSCI and NHS EOLC Programme January 2008. Duplicates have been removed and care homes are only counted once)



4.34 There are now many examples of innovative practice on which to build. These include:

- Five care homes managed by Risedale Estates in the North West of England, which have introduced the GSF, Preferred Priorities for Care (PPC) and LCP, with benefits for both staff and residents;
- Anchor Trust homes, which instituted a three day training programme for 300 staff during 2005 and 2006. This has helped remove the taboo surrounding death and encouraged staff and residents to deal with the topic more openly;
- Sue Ryder Care, which has involved 238 residents and over 300 nursing and care staff in six Sue Ryder Neurological Care Centres in improving end of life care – see Box 20; and
- A BUPA care home, local GP practice and specialist palliative care team in Whittlesey that have developed an integrated service to support residents with dementia and their families – see Box 21.

- 4.35 Although most of these initiatives are at a relatively early stage, those involved (both staff and residents) are clear about the beneficial impact. The challenge now is to spread what has been learned to ensure the benefits are realised across the whole of the care home sector.

**Box 20: Sue Ryder Care: Improving care for people with neurological conditions**

Sue Ryder Care is adapting the Gold Standard Framework for care homes (GSF-CH), LCP and PPC, to improve palliative and end of life care for people with neurological conditions living in six neurological care centres.

The project involves 238 residents, ranging in age from 20 years to over 85 years and over 300 nursing and care staff. It has sparked a renewal of interest from staff in palliative and end of life care, promoted the development and documentation of practice and kindled enthusiasm for further training. Induction programmes are now being delivered for new staff and an education programme for senior nurses is now running.

At the start of the project residents, their families and key local stakeholders were invited to project launch events. Links with OOH providers have been improved, with all residents at two centres now being on the local OOH database, allowing on-call doctors to have access to detailed information about a patient's neurological condition before visiting.

Three pilot centres have introduced the Preferred Priorities for Care tool. Ninety-nine per cent of residents recorded the care centre as their preferred place at end of life, while 1% wished to return to the family home.

The programme has demonstrated that the adapted GSF-CH tool is an effective and appropriate tool to facilitate high quality end of life care in neurological centres. The use of supportive care registers aids communication with OOH providers and ambulance crews.

Sue Ryder Care has recognised the importance of having robust processes to capture evidence of the quality of care they deliver and have developed a Care @ Death audit tool.

**Contact details:** Judi Byrne, Programme Lead.  
judi.byrne@suerydercare.org



**Box 21: A partnership approach to supporting residents with dementia in a specialist care home in Whittlesey, Peterborough**

A joint approach, which aims to support residents in The Gables BUPA care home, a 'specialist care' home for the elderly mentally ill, has been developed in Whittlesey. A local palliative care dementia group has been formed, whose membership includes staff from The Gables, a local GP from the Jenner Health Centre, Sue Ryder Thorpe Hall Hospice and other health and social care staff. The support of this group has enabled the GP and staff at the care home to develop an integrated service.

The core elements of the service include a regular GP ward round at the care home, use of advance care planning, including avoidance of unnecessary hospital admissions, and use of a modified end of life care pathway.

Training plays a critical role and includes support for staff in the use of a pain assessment scale and syringe drivers. Significant event meetings are open to all staff including carers, activities leaders and administrative staff.

A practical session is held with relatives to discuss a range of issues, including advance care plans, appropriateness of hospital admission, Do Not Attempt Resuscitation (DNAR) decisions and the end of life care pathway. Family members are made aware that time is available for individual discussions with the GP during the regular weekly ward round.

Discussions are now taking place with Peterborough PCT to roll this model out across the city. The agreement will stipulate standards of care, including the commitment of the practice to a regular session at the care home, use of the Gold Standards Framework and end of life care planning. Choice is preserved within the arrangement, as care home residents have the option to remain with their existing GP. Most, but not all, practices within the PCT have expressed interest in the agreement.

**Contact details:** Gillie.evans@nhs.net

## Challenges for care homes

- 4.36 Many care homes are enthusiastic about enhancing the quality of care they provide at the end of life. They recognise the benefits this can bring to staff and residents. Anecdotal evidence indicates that staff turnover rates may be reduced.

- 4.37 However, costs of training also need to be recognised, both in terms of trainers/facilitators and the time of care home staff who need to be trained.
- 4.38 Based on the experience of a number of care home chains, it is estimated that the cost to an average sized care home for staff to receive education, training and mentoring in the principles of end of life care, such as those set out in the GSF, LCP and PPC, would cost around £15,000 This is based on a cascade model, with a facilitator in each home who is responsible for the ongoing training of staff.
- 4.39 **Good PCTs, working with local authorities, will wish to commission services from care homes in which:**
- **Residents approaching the end of life are on an end of life care register;**
  - **Each resident is offered a care plan, which clearly identifies their needs and preferences for care;**
  - **Staff receive the training and support they need to provide end of life care; and**
  - **There is appropriate access to GP, district nursing and specialist palliative care advice.**

## Hospices

- 4.40 The modern hospice movement started with the foundation of St Christopher's Hospice by the late Dame Cicely Saunders in 1967. From the outset, the aim of hospices has been to provide high quality physical, psychological, social and spiritual care for people at the end of their life and to provide care both for the person and their families. It is important to note though, that there are inequalities in access to hospice care for certain groups of society. Hospices will therefore wish to consider what action they need to take to better promote their services to these groups.
- 4.41 Modern hospices do far more than provide pain relief to those at the end stages of life. They provide multidisciplinary, holistic care both within the hospice itself and often within the local community. Many hospices provide:
- Community specialist palliative care teams;
  - Hospice at home services;
  - Day care; and
  - Bereavement care.

- 4.42 In addition to providing direct care for people with complex problems, hospices and specialist palliative care services provide advice on other patients, for example, to district nurses and GPs. Many hospices also have an important role in providing education and training both for staff who wish to specialise in palliative care and those working in other areas who have significant roles in the provision of end of life care. Some specialists in palliative care (physicians and nurses) work directly alongside other clinical staff. For example, they may hold joint clinics or ward rounds with cardiologists, respiratory physicians or neurologists. Some hospices provide leadership in research, development and evaluation related to end of life care.
- 4.43 The large and sustained contribution of the voluntary sector to the development of hospices and specialist palliative care services and to the ongoing delivery of care, needs to be recognised. However, many hospices are finding it increasingly difficult to continue raising funds. Many also face uncertainty regarding the NHS contribution to their costs, as some PCTs only commit to short term contracts.
- 4.44 Needs for hospice and palliative care services vary markedly between PCTs. The National Council for Palliative Care has published indices of comparative resource need for all new PCT populations. These indices are based on annual mortality and relative socioeconomic deprivation. The findings indicate a variation in resource needed per head of population from 50% below average (Kensington & Chelsea) to 50% above average (Blackpool) for individual PCT populations. *Compendium of Data for SHAs and PCTs, NCPC (2006)*. [www.ncpc.org.uk](http://www.ncpc.org.uk)
- 4.45 The National Council for Palliative Care has compared levels of need with levels of provision of hospice beds for a sample of 22 PCTs, serving a combined population of 8.2 million and having access to 412 specialist palliative care beds. For around two thirds of PCTs bed provision was poorly matched with need, with some PCTs having over-provision and others under-provision compared with that indicated by the Index of Comparative Need.
- 4.46 Historically, hospices have predominantly cared for patients with cancer and relatively small numbers of patients with some neurological conditions, such as motor neurone disease. Around 16% of patients dying from cancer currently die in a hospice, compared with less than 1% of patients with circulatory or respiratory disease. This does not reflect the incidence, or severity, of problems in people dying with different conditions. Indeed, there is a considerable body of evidence showing that those with cancer and those with other diseases have similar problems in the last year of life.

The trajectories of different conditions do, however, vary. The predictability of prognosis towards the end of life is generally somewhat greater for cancer than for other conditions.

- 4.47 However, the challenge is to bring the expertise in specialist palliative care that has been developed for cancer patients to all people who may need it. There are some excellent examples of hospices delivering outreach services for people with conditions other than cancer. For example St Christopher's Hospice has developed a service for people with dementia.

#### **Box 22: St Christopher's Hospice – Dementia Project**

St Christopher's Hospice in South London, with financial support from the King's Fund, has established and evaluated a new model of working to meet the palliative care needs of people with advanced dementia and their families. This involves an outreach service provided by a peripatetic palliative care nurse specialist, supported by a consultant in palliative medicine. Criteria for referral are based on the Gold Standards Framework and an adapted 'surprise question' (see page 39).

An analysis of the first 50 patients has shown that referrals came from each of the homes for the elderly mentally infirm within the project area and from other care homes, a district general hospital and the community. Reasons for referral included symptom control, psychosocial support, terminal care, family and carer support and staff support.

Early findings from the project indicate that most people with dementia can be cared for at the end of their lives by staff who are not specialists in palliative care, but with specialist support. Very few people required ongoing support from the St Christopher's hospice at home service.

**Contact details:** [Victor.Pace@stchristophers.org.uk](mailto:Victor.Pace@stchristophers.org.uk)

### **The future role of hospices**

- 4.48 Hospices will continue to have a pivotal role within the new vision for end of life care set out in this strategy. They will continue to be centres of excellence, providing a standard of care against which other services will be measured. They will also continue to be key providers of education and research.
- 4.49 Over time, it is also anticipated that the case mix of people managed within hospices and by hospice trained staff will change, so that people are cared

for on the basis of need, rather than diagnosis. This should not, however, be done in such a way as to reduce the quality of care given to those with cancer. Nor is it envisaged that there will be a major expansion of the number of hospice beds across the country. Based on emerging experience in several parts of the country, we believe that other solutions can be found.

- 4.50 Several hospices have, over the past few years, entered into partnership arrangements with designated care homes. Staff in these homes are provided with additional training in end of life care and palliative care specialists may work in the home for several sessions per week. In this way, the holistic approach and skills of hospices are brought to a much wider range of people. In return, hospice staff can gain experience in the care of people with conditions which have not historically been referred to hospices.

**Box 23: Partnership between the Hospice of St Francis and Kilfillan Nursing Home**

The Hospice of St Francis, Berkhamsted, has developed a service model to improve the quality of care provided to residents of care/nursing homes who are approaching the end of life.

The hospice has agreed a contract with the local PCT to provide senior medical cover for ten continuing care beds in Kilfillan Nursing Home. The provision of regular input and continuing assessment by the specialist doctor and nursing team from the hospice has transformed the care which residents receive, enabling good symptom control and facilitating anticipatory prescribing.

Additionally, the hospice team provide training in end of life care for nursing home staff, including providing them with support in communicating effectively and sensitively with residents' carers and families.

**Contact details:** Yvonne Pettingell, Hospice of St Francis, Berkhamsted.  
yvonne.pettingell@stfrancis.org.uk

- 4.51 Hospices should not be expected to take on these new roles without adequate resourcing. Any new roles should form part of an agreed local strategy, which should be appropriately funded.
- 4.52 In summary, there will be new opportunities for hospices, working as part of an integrated locality. As independent organisations, voluntary hospices will

have the opportunity to take on new roles in agreement with their local PCTs. These new roles could include:

- Raising awareness of end of life care within the local community, such as is being done at St Christopher's Hospice in London;
- Providing a central coordination function for end of life care within a local health economy. This could include provision of 24-hour telephone helplines;
- Taking on new roles in enhancing the care provided within care homes;
- Taking on a wider role in education of non-specialists in palliative care;
- Innovative use of volunteers in care support programmes; and
- Taking on a wider role in the provision of carer support and bereavement care.

- 4.53 **Hospices will wish to consider what roles they might wish to undertake within local end of life care service delivery.**
- 4.54 **Good PCTs will wish to ensure that hospices are fully integrated in the strategic planning for end of life care services.**
- 4.55 **Good PCTs will wish to ensure that the uncertainties involved with short term contracts for voluntary hospices are removed. They should work towards three year rolling contracts, as set out in the Compact Code of Good Practice for commissioning with the voluntary sector.**

### Community hospitals

- 4.56 Community hospitals and other community based centres provide a valuable, but under-recognised resource in relation to end of life care.
- 4.57 There are over 330 community hospitals in England, which provide a range of facilities and resources, including inpatient care, outpatient care, day care and outreach services. Between 2001 and 2004, the Health Foundation funded a study to identify how community hospitals are involved in providing palliative and terminal care to older people with cancer and non-malignant diseases. One part of this project involved collecting the views of bereaved relatives from six community hospitals in the south of England.
- 4.58 A total of 51 bereaved carers were interviewed, all of whom were positive about the care they and the dying patient had received. The bereaved carers

particularly appreciated the location of the hospital (close to home), the availability of parking, the pleasant environment and the familiarity with staff. The care and kindness shown by community hospital staff was commented on specifically.

- 4.59 Between January and February 2007, the NHS Institute for Innovation and Improvement undertook a baseline survey which provides an up-to-date database of all community hospitals. The database of 266 returns provides information on the profile, staffing, size, location and services provided, including palliative care. One hundred and eighty one community hospitals stated that they provide palliative care. Further information is available at: [http://www.institute.nhs.uk/quality\\_and\\_value/productivity\\_series/survey.html](http://www.institute.nhs.uk/quality_and_value/productivity_series/survey.html)
- 4.60 Community hospitals have demonstrated their willingness to be involved in end of life care. Nearly 50% of them have already adopted the LCP. They now need to be integrated into local end of life care planning.
- 4.61 **Good PCTs will wish to ensure that the potential role of community hospitals in providing end of life care is recognised within local strategies. They will also wish to ensure that staff in community hospitals receive appropriate training in end of life care.**

## Ambulance services

- 4.62 As people approach the end of life their health needs generally increase, requiring more frequent access to health service providers. However, as their condition becomes more debilitating, access to services becomes increasingly difficult. Ambulance services and patient transport providers play a vital role in enabling those who are approaching the end of life to access the necessary care.
- 4.63 Current transport services do not always adequately support the provision of high quality end of life care. People at the end of life, due to the severity of their condition, often require transport by an emergency ambulance, crewed by a paramedic and technician, rather than vehicles crewed by fewer, or less highly qualified staff. However, people in hospital who wish to be transferred home to die may at times suffer delays waiting for an emergency vehicle to be made available. Delays may also be experienced by people who need transport to day care services in a hospice or hospital, or to hospital out-patient appointments, by non-emergency patient transport services.

- 4.64 At times, the person to be transported may request that their carer, or a family member, accompany them, or the carer or family member may express a wish not to be parted from the ill person. Whilst many providers will have policies on this area of care, a number will not.
- 4.65 Additionally, ambulance staff may not have access to the person's care plan and stated preferences, including DNAR decisions, which can mean that people's wishes in relation to their care may not be taken into account.
- 4.66 It is also anecdotally reported that some voluntary sector hospices have been charged by NHS transport providers for the costs of transporting NHS patients. Commissioners should be aware of Department of Health guidance on transport payments, including transfer of patients between NHS providers, hospices and people's homes. Information on this can be found in Chapter 20 of the *NHS Finance Manual* and the *Chief Executive Bulletin 10–16 May 2002: Guidance on Hospice Funding Issues*. Further clarification issued by the Department in the *NHS Finance Manual* in 2007 (section 20:42–20:44), advises on which PCT is responsible for meeting the cost of any given Patient Transport Services (PTS) journey to or from care homes, sheltered and extra care housing, hospices, social services facilities etc. The guidance states that nursing homes, residential homes and hospice facilities should not be considered as 'NHS organisations' and should be treated as if the patient was making the journey to and from home. If, exceptionally, patients are admitted to a hospice as a medical emergency, the costs will be covered by the PCT's service agreement for emergency ambulance services.
- 4.67 At the root of these issues are a number of problems with current services:
- Levels of service for end of life care are not specifically and clearly commissioned within service level agreements/contracts;
  - Information systems are not consistently in place across the country to support information exchange about patients with other healthcare providers;
  - There is not always sufficient focus on end of life care in the training given to those providing care and transport for these patients; and
  - Implementation of the Joint Royal College Ambulance Liaison Committee (JRCALC) guidelines (2006) on resuscitation of terminally ill patients could be given more attention and made more consistent.



**Box 24: Procedures for transporting patients with specialist palliative care needs in London Ambulance Service NHS Trust**

London Ambulance Service NHS Trust has produced guidance to meet the requirements of patients with specialist palliative care needs when they are being transported by ambulance.

It includes details of ambulance transfers between home, hospice, hospital and nursing or residential home, as well as dealing with a patient who is very ill, or dying, at home and what happens if the transfer itself risks the death of the patient. There is also a section on what to do if the patient has died at home. This covers the issue of when to attempt resuscitation.

The guidance, which is for patients who live in the South East London Cancer Network, aims to ensure that transfers are carried out quickly and preferably in the morning.

One underlying principle is that the patient, family and carers should be involved as far as is possible in all decisions concerning the transfer.

Central to good liaison is the 'Palliative Care Out of Hours Handover Form', which is completed by the patient's GP, district nurse or Specialist Palliative Care Team (SPCT) and faxed to both the London Ambulance Service and the GP out of hours service. A copy of the form may be found in the 'Message in a Bottle', a system whereby patients leave key information in an agreed place within a labelled container in the patient's fridge.

**Contact details:** Senior Clinical Advisor to the Medical Director.  
david.whitmore@lon-amb.nhs.uk (www.hpc-uk.org).

- 4.68 **For the transfer of patients going home from hospital to die, PCTs have an important role in contracting with providers to ensure a high standard of care. National work will continue to look at ways to support PCTs in this role.**
- 4.69 **To support the delivery of improved care, good commissioners of services will wish to ensure that all transport providers have in place policies for handling transport of carers, where they wish to accompany the person.**

- 4.70 **To ensure that ambulance staff or transport staff are aware of the needs and wishes of the person they are transporting and that the care they provide is appropriate, information systems should be adapted, or developed, to facilitate the sharing of patient information.**

### Prisons and secure hospitals

- 4.71 People who are detained in prison, or under the Mental Health Act in secure hospitals, should be treated with dignity and respect and given as much choice as is possible about the care they receive as they approach the end of their lives. This may mean that they will wish to end their days in what has become familiar surroundings and with those whom they know.
- 4.72 Mental health needs and learning disabilities are relatively more common in the prison population than in the general population. There is also a higher than usual incidence of substance misuse, with associated neglect of general health and dental care. Although the prison and secure hospital population mirrors the general population, there is some evidence to suggest that ageing and associated pathology may be accelerated. The prison population includes over 7000 people (men and women) aged 50 or more, of whom over 400 are over 70. Older prisoners experience accelerated ageing, which means that they experience issues associated with older age from 50 onwards. Around five out of six (85%) of older prisoners have a longstanding illness or disability.
- 4.73 Some health services within prisons have been able to meet the needs of prisoners and have enabled them to receive appropriate care, either in the prison, local hospital, hospice or in their own family home on a compassionate release order (see Box 25). In addition, to improve the physical environment for people serving sentences at the end of their lives, Albany Prison on the Isle of Wight has been selected to take part in the next phase of the King's Fund's Enhancing the Healing Environment programme.
- 4.74 To support improved end of life care for prisoners, the Department of Health and the Prison Service are working together to ensure that the principles, as set out in this strategy, are applied to prisoners.
- 4.75 **Good PCTs, working in partnership with local prisons and secure units, local hospitals, hospices and coroners, will wish to set out a plan of action to provide end of life care, which respects the dignity of the individual and recognises the changing requirements of detention when the person is dying.**

### **Box 25: Norwich Prison**

Recently, Norwich prison established a 15-bed unit for older people serving a life sentence. The intention is to provide care for these people until they die, recognising that as death approaches the person may wish to choose whether to be cared for in the familiar surroundings of the prison, or in the local hospital or hospice.

Recognising the importance of choice and working in partnership with the local PCT, hospital, hospice, ambulance service and coroner, the unit is able to provide appropriate care for the person. The staff have all been trained by the local hospice in the basic principles of end of life care and are able to refer to hospice medical and nursing staff for advice and additional support. The Gold Standards Framework and Liverpool Care Pathway for the dying are established within the unit. Personal preferences about care are discussed with the person and, where appropriate, with families, about resuscitation, who they would like with them and where they would prefer to die. Families and friends are able to visit regularly as death approaches and to spend time quietly with the person after death to pay their last respects.

This unit is the only one of its kind within the UK prison system and is currently receiving people from other prisons for end of life care. The future vision of the prison is to be able to extend services to provide assisted care for older people and those suffering from long term chronic conditions, similar to the care provided within a care home.

Since the unit opened in August 2004 there have been ten deaths. Three prisoners chose to be transferred to the local hospice, Priscilla Lodge, to die.

**Contact details:** Debby Jaques or James Shanley.

debby.jaques@hmps.gsi.gov.uk

james.shanley@hmps.gsi.gov.uk

## **Hostels for the homeless**

- 4.76 Homeless people are vulnerable and can have a multitude of physical and mental health problems, including those related to substance misuse. People who have experienced long term homelessness (particularly rough sleeping) tend to die younger. It has been suggested that the average age of death

for homeless people is 42 years. Often homeless people will have behaviours associated with personality disorders, learning disabilities and poor literacy and as a result, they are often labelled as difficult. Their treatment at the end of life is often undignified.

- 4.77 Many people who are homeless are not registered with a GP, so it is difficult for appropriate health and social care support to be put in place, or for relevant referrals to be made. Many are 'invisible' to the health and social care system and therefore difficult to identify when end of life is approaching. Additionally, discharge planning from hospitals to hostels is not always done well. As a consequence, hostel staff may be unaware that the person is dying and subsequently find the person dead in their room a few days following discharge from hospital. Death in this way is neither dignified for the individual, nor easy for the member of hostel staff who discovers the body.
- 4.78 Whilst some homeless people will want their families to know they are dying, others may not. For many homeless people, they will have either lost contact with family, or have made a choice to remain estranged. Therefore, it is important for them to have access to advocates, such as those provided by the St Mungo's charity for the homeless in London, to help them in the care planning process. In assessing the needs of the homeless, health and social care workers should not make assumptions about who the person would like to make contact with and who their main carer (if at all) may be.
- 4.79 **Health and social care staff, working in partnership with organisations supporting homeless people, should ensure that a comprehensive assessment of the person's needs and preferences for end of life care are communicated to all relevant agencies.**
- 4.80 **Education, training and support is required for health, social care and hostel staff in understanding the specific health, social care and behavioural needs of homeless people.**
- 4.81 **Good PCTs will wish to ensure that local strategies for end of life care encompass the needs of the homeless.**



# Chapter 5: Support for carers and families

## Introduction

- 5.1 Carers and family members of a person who is approaching the end of life can have a vital role in enabling that person to die in the place of their choice. They also have their own needs. Many carers willingly take on the role of looking after someone close to them who is nearing the end of life. However, the physical, psychological, social, financial and spiritual consequences of doing so need to be taken into account.
- 5.2 All carers are likely to become tired and find it difficult to continue without additional support. Some carers, particularly those who are older, may suffer from pre-existing ill health. The needs of child carers should be given particular consideration, so that they do not take on more than they can reasonably cope with.
- 5.3 Three key principles should apply to carers of people approaching the end of life. These are that:
- Carers are central to the team that cares for somebody at the end of life and they should be treated as 'co-workers' with the health and social care team;
  - Carers have their own needs. Those providing a substantial amount of care on a regular basis are entitled to a community care assessment by their local authority; and
  - The condition of the person who is cared for should not affect how the carer is treated, or the services the carer may be able to access.
- 5.4 It should be recognised that not all carers are family members and that not all family members are carers. Family members may have needs for psychological and social support that are separate from those of the carer or the person who is being cared for. It should also be recognised that the carer's needs and wishes may conflict with those of the dying person and perhaps the rest of the family and will need to be managed carefully.

## Information and communication with carers

- 5.5 Discussions about end of life care with patients and carers will depend on individual circumstances, the nature of the illness and the relationship between the person nearing the end of life and the carer. Carers should be included in any planned discussion with the dying person and subsequently provided with support. Carers will have varying levels of need and support depending on individual circumstances.
- 5.6 It should be recognised that the carer and the person being cared for may have different attitudes and wishes about end of life care, which could make open discussion difficult. Some carers may be extremely fearful about raising the subject and feel they do not have the skills to do so. In these situations, carers may need help to think through issues and ask the right questions.
- 5.7 Carers need information about the illness itself and what to watch out for, if they are to carry the ongoing responsibility for care. They need factual information to plan their own lives and in order to be prepared for different eventualities. This may include information on the likely course of the illness, benefits, work issues, what to do when someone dies and other practical matters. The dying person may also have children and it will be necessary for their school to be informed so that the school is aware of the stress which the child might be under and provide the necessary support.
- 5.8 Information needs to be available in a variety of formats and through a variety of channels if it is to reach those who need it at the right time. For many people telephone helplines will be the most appropriate source. Others may prefer to use the NHS Choices website ([www.nhs.uk](http://www.nhs.uk)) for information on health and social care options, presented through a pathway approach. Cruse Bereavement Care also provide accessible information and support ([www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)).

### **Box 26: Bridges Support Service in the Sandwell and Birmingham area**

The Bridges Support Service offers a wide range of support services to patients with cancer and other palliative care needs in the Sandwell and Birmingham area.

The Bridges model aims to make life easier for patients, their families and carers in the community and improve or maintain the quality of life throughout the patient journey – from diagnosis, remission and palliative care to death and beyond.

The service, first set up in Sandwell in 2001, provides a wide range of supportive care services, including respite care, domestic care, sitting service, benefit advice, advocacy, volunteer transport, counselling, information, complementary therapy and self help support, as well as referrals and access to mainstream health and social care services.

The service was originally set up to provide support to people with cancer, but this was later widened to those with other conditions. It is now being expanded into Heart of Birmingham PCT as part of a three year plan to integrate it into all aspects of the city's cancer and palliative care services. The plans have been developed in partnership with the Pan Birmingham Palliative Care Network, PCTs, Murray Hall Community Trust and Macmillan Cancer Support.

**Contact details:** Manager, Bridges Support Service  
(manjulapatel@nhs.net)

- 5.9 Some carers may face significant losses both during the time they are caring for someone and subsequently. They need support and space to be able to discuss their feelings about losing the person and may need help in arranging financial and legal matters. Not being able to participate in local activities, or meet colleagues and friends, means that a carer can become isolated. This isolation can be heightened once the person they care for has died. There is some evidence to suggest that assessing and addressing these issues early and providing appropriate support, is preventative healthcare, helping carers to prepare for their loss. This is helpfully set out in *Guidance for Bereavement Needs Assessment in Palliative Care*.<sup>5</sup>

5 *Guidance for Bereavement Needs Assessment in Palliative Care*. Relf et al Help the Hospice (2008).



- 5.10 Carers' needs and ability to cope, including their own health and emotional wellbeing, should be reviewed and discussed at significant stages of the pathway, such as at the point of diagnosis, during treatment, when the illness is advanced and when the likely outcome is death. The carer, cared for person and any professional involved in the care should feel able to request a meeting to discuss care at any time.
- 5.11 Since October 2007 Local Authorities (LAs) have had funds to support carers in a crisis or emergency situation. It is important that emergency plans are discussed with carers, so they can be assured a plan is in place if they are suddenly unable to provide care. This might include practical help from Crossroads' schemes, utilising community hospital services, or extending some of the hospice at home type services to a wider population of people.
- 5.12 The care plan for the carer should include discussion about the patient's wishes for organ donation and practical arrangements at the time of death and support afterwards. This should include discussion about any cultural/faith issues.

## Care delivery

- 5.13 When someone is admitted to a hospital, or a care home, there is a danger that the carer may lose their status and be excluded, or have less access than they wish. Provider organisations should involve carers in whatever capacity the carer wishes, in liaison with the patient and provide flexible facilities to provide comfort and hospitality and if necessary overnight accommodation. Provider organisations will also wish to be aware of the possibility that the individual and carer might be in a gay or lesbian relationship and that the main carer may be the patient's partner and not a family member.
- 5.14 Conversely, when caring for a person at home, the carer may feel overwhelmed by the responsibility of caring and unsettled by the disrupted normality of the home. Carers need to feel confident and so may need help with practical skills, such as lifting and washing. They also need to understand about the medicines the person is taking and any side effects and in some cases, where the patient wants, be involved in the decisions about the medicines prescribed for the patient. Most importantly, carers need to know when and who to call if they have any concerns and this facility should be available 24/7. Analysis of calls made to rapid response teams which are part of Marie Curie Cancer Care's Delivering Choice Programme has shown that around one quarter of all calls were from carers needing psychological support. Some hospices have also audited their out of hours calls and visits and found that a significant number are from carers needing psychological support.

## Last few days of life

- 5.15 The last days of life are a time when a care plan is most important and communication and coordination paramount, with health, social care, and voluntary agencies working together. It should be recognised that the needs of the carer may be very different from that of the person they care for at this point. Some carers will need support in practical ways as they 'watch by the bedside', including guidance on how to handle specific scenarios.

### **Box 27: Supporting carers in East Cheshire**

East Cheshire Crossroads Macmillan Palliative Care Service helps carers to ensure that a relative with a terminal illness remains in their own home, if that is their preferred place of death.

The team of ten trained support workers support carers of people who have advanced palliative care needs, whether they are already at home, or awaiting hospital or hospice discharge. The staff are trained to provide practical and emotional support to the family and be as supportive, flexible and unobtrusive as possible.

During a care visit Crossroads staff can provide personal care, 'double-ups' with the district nurse, respite for the carer, or do practical tasks such as light domestic duties or shopping.

Funding is provided by the Primary Care Trust (PCT) through a service level agreement. Macmillan provides additional funding.

It is hoped to extend this support to people with dementia with palliative care needs and their carers. There are also plans to increase staffing levels, particularly in relation to overnight respite breaks and weekend work.

Feedback from service users indicates the service is popular and that uptake is increasing.

**Contact details:** [help@eccrossroads.org.uk](mailto:help@eccrossroads.org.uk)

## Care after death and bereavement

- 5.16 During the first few days after death, the carer may need specific support. Suddenly the 'work stops' and there is a loss of identity, in addition to the loss of the person. A care plan needs to include practical information

about arrangements for collection of any equipment and disposal of unwanted/unused medicines after death, as well as providing emotional and psychological support.

- 5.17 Bereavement care and support need to be readily available and offered to all carers, family members and close friends. This is particularly important for children facing and then coping with the death of someone important in their lives.

**Box 28: Implementation of bereavement befriending service in North Tyneside**

In response to a needs assessment which showed people waited too long for bereavement support, a team was established to support people in North Tyneside. The service consists of a full-time programme coordinator and part-time assistant coordinator. They are supported by a team of 37 volunteers, who give on an average two hours a week to bereavement support and between them have provided over 1300 bereavement support visits over the last three years.

Ongoing education and support including supervision sessions, support group meetings and regular education sessions are provided for volunteers.

In addition, all referrals are screened to ensure they are appropriate for volunteers. If the cases are particularly complex they will be referred to other services.

The team has also begun to work with learning disability services and now offers bereavement training for staff working in this area.

The service has been funded for the past three years by Macmillan Cancer Support, but from 2007/08 this will be taken on by North Tyneside PCT.

**Contact details:** Bereavement Service Coordinator  
lisa.johnstone@northtyneside-pct.nhs.uk

- 5.18 A vital issue in good care after death is the provision of appropriate and comprehensive bereavement care. Currently, staff dealing with carers and families of the deceased do not always have the confidence and skills to support them appropriately. Therefore, all staff dealing with the bereaved, including bereavement officers, should be given training on how to provide

support including accessing comprehensive spiritual, emotional, practical and financial support.

- 5.19 Staff should also be aware that families and carers of people who have died suddenly and unexpectedly, such as through suicide or in an accident, may well have markedly different needs than those who die from a recognised long term terminal condition. Equally, although not necessarily unexpected, deaths from large scale pandemics will generate different support needs for carers and families who may be suffering illness themselves, in addition to coping with bereavement. The 'care after death' section in the Liverpool Care Pathway for the Dying Patient (LCP) can be utilised for all deaths, expected and sudden, and in all settings. In addition, the Department of Health has produced a resource for people bereaved by suicide and other sudden, traumatic death: *Help is at Hand: a resource for people bereaved by suicide and other sudden, traumatic death* (2006). Ambulances services and the police also provide leaflets to families when a death is unexpected.
- 5.20 The specific needs of bereaved children and adolescents should also be recognised and information and support given in a way that is sensitive to their maturity and level of understanding. Staff should be aware that adolescents may wish to be fully included in all the processes around the death and that their remaining parent or guardian/s may need support to understand this need. Additionally, in cases where the child or young person has been a key caregiver at home, this role should be respected at the time of death and in planning arrangements after the death.
- 5.21 **Carers should be offered an assessment of their needs and a formal 'carers care plan' either with, or separately, from the cared for person. This should set out times for review, including plans for support of the carer after the death of the person.**
- 5.22 **Systems and resources need to be in place to ensure that services to meet assessed needs, for example, equipment, additional support, breaks for carers, interpreters, are available when required.**
- 5.23 **Health professionals should advise carers and families about the process for dealing with unwanted medicines after the person dies.**
- 5.24 **All staff in health and social care, and the voluntary and independent sectors, need some training to ensure they are able to communicate effectively with people who are dying and their carers about issues surrounding end of life care.**

- 5.25 **Information on how to access comprehensive and culturally appropriate bereavement and support services should be available from all health, social care and other emergency organisations providing care at the end of life and into bereavement. This should include support for those bereaved through sudden death and also the needs of children and the challenge of parenting them.**
  
- 5.26 **Information on bereavement and support services should be available through a range of formats and channels, including 24/7 helplines and the NHS Choices website.**
  
- 5.27 **Good PCTs will wish to ensure that local strategies for end of life care encompass the needs of carers and families. They may also wish to read the Carers Strategy, published by the Department of Health in June 2008** ([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085345](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345)).

# Chapter 6: The end of life care workforce

## Introduction

- 6.1 A cultural shift in attitude and behaviour related to end of life care must be achieved within the health and social care workforce. Death is inevitable and does not necessarily constitute a failure of care. Indeed, one of the key roles of health and social care staff is to help patients, as far as possible, to come to terms with the transition from life to death. Providing end of life care can evoke strong emotions amongst care givers. Although frequently sad, if staff have the necessary knowledge, skills and attitudes it can also be immensely rewarding.
- 6.2 There is widespread agreement on the importance of workforce development to the overall success of this End of Life Care Strategy and an acknowledgement that there are major deficiencies in the knowledge, skills, attitudes and behaviours of staff groups who come into frequent contact with people at the end of their lives. The focus, therefore, relates more to training and development issues across all the statutory and independent sectors involved in end of life care services, than on an expansion in the workforce.
- 6.3 Within health and social care there are approximately 2.5 million staff. Of these, only 5500 staff work in specialist palliative care services and essentially spend the whole of their working lives dealing with end of life care. These staff have the required expert knowledge and skills and will be essential in supporting the development of the wider workforce.
- 6.4 Development of the end of life care workforce will take time, but that must not be taken as an excuse for inaction. Programmes to skill up existing staff groups (including both registered and non-registered staff) will translate through into early benefits for patients and carers. This is already being seen through the application of tools such as the Gold Standards Framework (GSF), Preferred Priorities for Care (PPC), and Liverpool Care Pathway for the Dying (LCP), in primary care, hospitals and care homes (see chapters 3 and 4). In addition, the Social Care Institute for Excellence (SCIE) also has a useful role in identifying models of good practice, which can support workforce development.

- 6.5 Programmes to enhance training for medical undergraduate/postgraduate and other professional pre-registration students will take longer to demonstrate benefits for people approaching the end of life, but are of equal importance in the long term.
- 6.6 This chapter outlines the broad programme of workforce development that needs to be instigated to ensure that all staff caring for people approaching the end of life have the necessary knowledge, skills and attitudes. This will need to involve a wide range of organisations at national, regional and local levels across statutory and independent sectors. Key responsibilities for different aspects of this programme are as follows:
- **The professional regulators** (General Medical Council (GMC), Postgraduate Medical Education Training Board (PMETB), Nursing and Midwifery Council (NMC), General Social Care Council (GSCC) and the Health Professions Council (HPC) will need to consider if end of life care is given appropriate priority within relevant standards and outcomes and that the assessment of competence is sufficiently rigorous;
  - **Providers of higher education** (Medical Schools, Postgraduate Deaneries and other Higher Educational Institutions) will need to consider if educational programmes deliver the required learning outcomes and that adequate time within the curriculum is made available for this. They will also need to review whether knowledge, skills and attitudes are appropriately assessed;
  - **Strategic Health Authorities (SHAs)** will want to ensure that appropriate programmes of education are commissioned, taking account of the needs of staff working in hospitals, the community, care homes, hospices and any other settings where people may die;
  - **Employers** will need to ensure that both registered and non-registered staff have the necessary skills and competences and are given access to appropriate training opportunities;
  - **Skills for Care and Skills for Health** will need to develop core principles and competences to underpin training and workforce development. They should work closely with the **Academy of Medical Royal Colleges** and other professional organisations on this; and
  - **e-Learning for Healthcare** should look at how it can support training across health and social care. Given the numbers of staff involved, this will be key to delivering training.

- 6.7 Staff delivering any aspect of end of life care have a responsibility to ensure that they have the necessary skills and competences to enable them to deliver high quality end of life care. If they are registered with an appropriate professional body, they should also ensure that they can demonstrate this for the purposes of revalidation/recertification.
- 6.8 To determine how best to drive forward the workforce development agenda, we need to review current practice within the UK and to learn from other countries. For example, a recent initiative in Canada, Educating Future Physicians in Palliative and End of Life Care (EFPPEC), also included an interprofessional model on advance care planning that may be particularly relevant.

### **The end of life care workforce**

- 6.9 A very large number of health and social care staff, working in the community, in hospitals, care homes, hospices and other places, have at least some role in the delivery of care to people at the end of their life or their families and carers. Doctors, nurses, allied health professionals, pharmacists, social care staff, chaplains, ambulance staff, porters, mortuary staff and others, including those within the voluntary sector, all have essential roles. Each staff group must have the necessary knowledge, skills and attitudes to fulfil their roles effectively.
- 6.10 The end of life care workforce can be segmented into three broad groups. The following table highlights the three groups and the suggested minimum levels of skills and knowledge required:



**Table 4: Workforce groups**

Group definition	Minimum levels of skills and knowledge
<p><b>Group A – Staff working in specialist palliative care and hospices who essentially spend the whole of their working lives dealing with end of life care. This includes:</b></p> <ul style="list-style-type: none"> <li>● Physicians in palliative medicine, palliative care nurse specialists and allied health professionals, hospice pharmacists, senior palliative care pharmacists, chaplains and all health and social care staff working in or with hospices.</li> </ul>	<ul style="list-style-type: none"> <li>● All staff should have the highest levels of knowledge, skills and understanding through specialist training as part of further specialist registration and/or continuing professional development (CPD).</li> <li>● These should include communication skills, assessment, advance care planning and symptom management as they relate to end of life care.</li> </ul>
<p><b>Group B – Staff who frequently deal with end of life care as part of their role. This includes:</b></p> <ul style="list-style-type: none"> <li>● Secondary care staff working in A&amp;E, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, long term neurological conditions, intensive care, hospital chaplains and some surgical specialities.</li> <li>● Primary care staff including GPs, district nurses, community matrons, some care home staff, ambulance staff and community based carers.</li> <li>● Specialist nurses, such as heart failure nurses, based in primary or secondary care.</li> <li>● Community pharmacists.</li> </ul>	<ul style="list-style-type: none"> <li>● Staff will need to be supported to enable them to develop or apply existing skills and knowledge to end of life care through CPD, or further specialist training and overcome any personal or team barriers.</li> <li>● This group has the greatest potential training need, in particular secondary care doctors (and their immediate teams), GPs (and teams) and district nurses, who may be key in the ‘trigger’ discussion at the start of the pathway and with ongoing continuity of care.</li> <li>● These should include communication skills, assessment, advanced care planning and symptom management as they relate to end of life care.</li> </ul>

Group definition	Minimum levels of skills and knowledge
<p><b>Group C – Staff working as specialists or generalists within other services who infrequently have to deal with end of life care. This includes:</b></p> <ul style="list-style-type: none"> <li>● Other professionals working in secondary care or in the community, for example, care home staff and extra care housing staff, day centre and social care staff not involved in hospices, as well as domiciliary care and prison services staff.</li> </ul>	<ul style="list-style-type: none"> <li>● This group must have a good basic grounding in the principles and practice of end of life care and be enabled to know when to refer or seek expert advice or information.</li> <li>● Many of the staff within care home settings and providing domiciliary care in this group have significant unmet training needs, including access to induction programmes.</li> </ul>

## Core principles and competence frameworks

- 6.11 One of the most pressing tasks now is to define the core principles and competence required by each staff group as they interact with the end of life pathway. Many of the core principles and competences will apply across professional groups and it is recommended that this work should be undertaken by Skills for Care and Skills for Health, working in collaboration with the Academy of Medical Royal Colleges.
- 6.12 Four areas have been identified as core common requirements for workforce development:
- Training in communication skills – basic, intermediate and advanced level as appropriate;
  - Assessment of the person’s needs and preferences;
  - Advance care planning; and
  - Symptom control.
- 6.13 In particular, consideration will need to be given as to how these break down to reflect the knowledge, skills and attitudes required to undertake each of the following roles:
- Initiating discussions about end of life issues;

- Assessment of the person's needs and preferences and advance care planning;
  - Coordinating care;
  - Delivery of physical, psychological, social and spiritual care to patients;
  - Delivery of care in the last days of life;
  - Delivery of care after death; and
  - Assessment of carers' needs and provision of care to carers both during a patient's life and after death.
- 6.14 Alongside competences that relate specifically to end of life care, broader competences regarding team working, clinical decision making and management will also need to be considered.
- 6.15 **To take this forward, the Department of Health has commissioned Skills for Care and Skills for Health to lead a joint project to identify a set of common core principles for end of life care and the competences that will inform the development and commissioning of appropriate training programmes. The work should be completed by June 2009.**

### Education, training and continuing development

- 6.16 Almost all health and social care staff will at some time care for someone who is approaching the end of life. Therefore, a basic knowledge and awareness of end of life care needs to run through all undergraduate and pre-registration training to prepare staff for this eventuality.
- 6.17 Guidance on standards and outcomes from the professional regulatory bodies, the GMC, NMC, GSCC and HPC, informs the undergraduate and pre-registration curriculum development by education providers. These high level statements can be interpreted by the education provider to determine curriculum content. Many of the standards refer to proficiencies/skills that can be applied to end of life care, but are implicit rather than explicit.
- 6.18 The White Paper, *Trust, Assurance and Safety – the regulation of health professionals in the 21st century*, published in February 2007, proposed a system of revalidation, in which all the regulated health professions would be required periodically to demonstrate that they continued to be fit to practise. The Department of Health is currently working with the professions and their regulators to develop detailed proposals. Communications skills are likely to

be an important component of the revalidation process. So, for example, all doctors will undertake multi-source (or 360 degree) feedback from patients and colleagues to assess their skills. For those medical specialties where end of life care is particularly important, the relevant medical Royal College may choose to emphasise these components when revalidating their specialist certificate.

- 6.19 Similarly, regulators of other professions across health and social care will wish to consider how to ensure that the skills required for effective and sensitive care are sustained and kept up to date throughout professional careers.

### Undergraduate medical training

- 6.20 The GMC is responsible for setting the standards and outcomes for undergraduate medical education in the UK. *Tomorrow's Doctors* (2003) outlines the requirements for curricular content, structure and delivery and sets out the knowledge, skills, attitudes and behaviours expected of medical graduates in order to gain entry to the profession.
- 6.21 There are a number of areas within *Tomorrow's Doctors* that are relevant to the provision of end of life care. In particular, paragraph 16 provides that:
- 'Graduates must know about and understand the principles of treatment including the following:
- How to take account of patients' own views and beliefs when suggesting treatment options;
  - The effective and safe use of medicines as a basis for prescribing;
  - Relieving pain and distress; and
  - Palliative care, including care of the terminally ill.'
- 6.22 The GMC does not prescribe how medical schools should develop their undergraduate programmes to deliver the requirements in *Tomorrow's Doctors*. However, discussions with representatives of individual medical schools have revealed wide variations in the time allocated to palliative and end of life care training. In some schools, all students receive two to four weeks education in palliative medicine in a block. In other schools, medical students may receive hardly any formal training in palliative care, with perhaps an optional visit to a hospice. Most importantly, students may not be assessed on their competence in end of life care.

- 6.23 A review of *Tomorrow's Doctors* by the GMC has started. Phase 1 will inform the development of a revised draft and Phase 2 will see the publication of the revised draft for consultation. The consultation should commence in late 2008 and a new edition will be published in 2009. The End of Life Care Strategy should be seen as an opportunity to influence the review and ensure that the standards and outcomes contained in the new edition of *Tomorrow's Doctors* are reflective of the future medical workforce needed to support high quality end of life care.
- 6.24 It is important to recognise that a newly qualified doctor on the first day of their Foundation Year One (FY1) programme may be faced with a dying patient and a distressed relative. He or she may also have to deal with a patient who has just learnt that they have an advanced, incurable illness. These doctors need to have the necessary core competences to enable them to deal with these situations without adverse consequences for the patient, family members and themselves.
- 6.25 **Therefore:**
- **All relevant professionals, service commissioners and providers should ensure they contribute to the consultation on revisions to *Tomorrow's Doctors* taking place in 2008.**
  - **The GMC and the Academy of Medical Royal Colleges will want to define the competences related to end of life care required by a newly qualified doctor. Work undertaken by the Association for Palliative Medicine of Great Britain and Ireland on the *Consensus Syllabus for Undergraduate Palliative Medicine in Great Britain and Ireland* should support this work.**
  - **Deans of Medical Schools will want to review their curricula to ensure that sufficient time and opportunity is given to end of life care so that newly qualified doctors have the necessary competences. They will also want to consider whether these competences are being adequately assessed.**
  - **The GMC will want to consider whether end of life care should be included in its quality assurance visits to medical schools. These provide opportunities to identify examples of good practice and to disseminate these more widely amongst other medical schools.**

## Postgraduate medical training

- 6.26 After graduation there is a two year training period – The Foundation Programme – during which doctors prepare for full registration with the GMC (on completion of F1) and for entry to specialty training programmes (on completion of F2). The GMC is responsible for setting the educational requirement for F1 and the PMETB is responsible for F2.
- 6.27 The standards that Postgraduate Deaneries delivering the Foundation Programme must meet and the outcomes that doctors must demonstrate at the end of F1 in order to be eligible for full registration are set out in *The New Doctor* (2007). This is due to be reissued in 2009. This will provide an opportunity to review criteria relating to end of life care for full registration as a doctor.
- 6.28 The GMC and the PMETB have joint responsibility for quality assurance of the Foundation Programme. This provides a potential opportunity to focus on end of life care.
- 6.29 Further training in end of life care after the Foundation Programme is particularly important for doctors undertaking specialist training in any of the disciplines identified as being in Group B (i.e. dealing with end of life care on a frequent basis) in paragraph 6.10.
- 6.30 End of life care is explicitly part of the new GP curriculum *The Royal College of General Practitioners – Curriculum Statement 12 – Care of People with Cancer and Palliative Care* (2007), which contains key messages relating to terminal care and helping patients die with dignity and minimal distress.
- 6.31 **The PMETB and the Academy of Medical Royal Colleges will want to ensure that a common competence framework for end of life care is developed covering all of the disciplines classified within Group B. They will need to ensure that this work is complementary to the project led by Skills for Care and Skills for Health. They will also want to consider what training trainers will require in this area and how trainees' competence can best be assessed, for example, through Penultimate Year Assessments.**
- 6.32 **Postgraduate Deaneries will also want to influence curriculum development, ensuring training programmes deliver medical practitioners with appropriate levels of skills and understanding related to end of life care.**

## Pre-registration training for non-medical professions

- 6.33 The NMC produces *Standards of Proficiency for Pre-registration Nursing Education*, and is also introducing Essential Skills Clusters for Pre-Registration Nursing programmes (NMC Circular 07/2006), to enable education providers and those providing supervision and mentorship to support the achievement of nursing standards. There are no explicit statements relating to end of life care in the standards, but there is an implicit expectation of all programmes. In addition, the NMC is undertaking a review of pre-registration nursing education, in association with Modernising Nursing Careers, that will give an opportunity to discuss end of life care training for nursing staff. The project is likely to take two years and the new Standards may be published in September 2009. The first stage of the consultation ended in February 2008 and a statement from the NMC is expected in June 2008. **This will inform the second phase, due to start late in 2008 and all interested parties should contribute to the consultation when published.**
- 6.34 The HPC sets standards for proficiency, education and training, and continuing professional development (CPD) for the 13 professions it currently regulates. The HPC undertook a consultation on its standards between October 2006 and February 2007 and new standards were published in late 2007. Many of the standards can relate and be applied to end of life care, but are not explicit.
- 6.35 The degree for social workers is based around Skills for Care National Occupational Standards (NOS). The GSCC accredits education providers and monitors training against these standards. The degree is achieved through a combination of university and assessed work place practice. A key requirement is a section on values and ethics, which can be applied to end of life care and includes a standard to 'support individuals through the process of dying'.
- 6.36 Nurses, allied health professionals, pharmacists and social workers who have just achieved registration may be faced with a dying patient, or someone who has just learnt that they have an incurable illness, on the first few days out of training, or whilst on clinical/work placements. Each of these groups needs to have the necessary core competences to enable them to deal with these situations without adverse consequences for the patient, family members and themselves.

- 6.37 **The standards set by the regulatory bodies for non-medical professions are high level statements that can provide maximum flexibility for education providers, commissioners and placement providers to allow them to respond to local and national drivers in developing and updating programmes. Good education commissioners and providers of education will wish to utilise this flexibility to ensure that end of life care is a thread running through all programmes and staff are adequately prepared.**

### Continuing professional development

- 6.38 Health and social care staff who have completed formal training and entered a professional register are required to keep their knowledge and skills up to date throughout their working lives. During the development of this strategy, it has become clear that many senior clinicians (doctors, nurses and others) lack some of the essential competences required for the delivery of high quality end of life care. Therefore it is important that end of life care is part of CPD initiatives for all professionals and includes communication skills, assessment, advanced care planning and symptom control where appropriate to their role.
- 6.39 In particular, it became evident that professionals in Group B specialty areas should be given a high priority and **particular emphasis should be placed on training in advanced communication skills to enable staff to initiate discussions with patients about end of life care issues.**
- 6.40 A successful model for advanced communication skills training for senior healthcare professionals has been developed over the past few years in the field of cancer. This model involves:
- A three day, learner centred course, focusing on specific issues which the learner identifies as being a problem or difficulty;
  - Role play, with actors taking the part of simulated patients; and
  - Video recording so that participants can observe their own performance.
- 6.41 The model has been shown through randomised controlled trials to be effective in improving the communication skills of both doctors and nurses. A cascade approach to dissemination of training has therefore been initiated, with a significant cadre of facilitators being trained to lead courses for senior healthcare professionals.



- 6.42 The model will be further developed for training in communication skills related to end of life care and piloted over the next two years. If successful, it would provide a model of training for all relevant groups of senior healthcare professionals.
- 6.43 As well as communication skills training, all relevant staff involved with end of life care should be able to undertake a comprehensive assessment of the needs and preferences of a person relating to physical, social and occupational, psychological and spiritual wellbeing. The assessment needs to be iterative, non-mechanistic and over a period of time.
- 6.44 As described in chapter 3, it is important to elicit a person's preferences regarding both the type and location of care. The skills required for this are helpfully set out in *Advance Care Planning: a guide for health and social care staff* (February 2007), (website shown). It identifies the different levels of skills that are required for differing levels of practice, so that staff have the ability to recognise their skills and limitations and how to identify complex needs, even if they are unable to identify them themselves.  
([www.endoflifecareforadults.nhs.uk/eolc/files/AdvanceCarePlanning.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/files/AdvanceCarePlanning.pdf))
- 6.45 The consultation period for the document *Towards a Framework for Post Registration Nursing Careers*, which had end of life care as a cross cutting theme, was completed in February 2008. Work is currently progressing to identify key recommendations and how best to take forward the next steps that will inform further training developments.

### **The specialist palliative care workforce**

- 6.46 A joint survey, undertaken by the Department of Health and the National Council for Palliative Care in 2005, indicated that around 5500 staff work in specialist and palliative care services. This specialist workforce cannot and should not provide all the care needed by people approaching the end of life. However, they do have a vital role in providing care for people with the most complex problems and in providing education for staff who are not specialists in palliative care.
- 6.47 The training needs of specialist staff, which could include chaplains, who undertake a major role in the development and mentorship of other groups need to be recognised and adequately resourced.

- 6.48 **SHAs and postgraduate deaneries should support the development of training to enable this group of staff to undertake this developmental role.**

### Training for unregistered staff groups

- 6.49 Many health and social care support workers, care home staff and other unregistered staff groups, including those working in the voluntary sector, have significant unmet training needs. Some will have few if any competences and will be starting from a low baseline, although they may be key to providing care in domiciliary settings.
- 6.50 **Staff should be provided with induction programmes when they start work that includes basic and intermediate communications skills training, as well as an understanding of care planning.** It is also important that these staff are adequately supported to know how and when to access advice and support from specialists.
- 6.51 Deaths can occur in areas where they are least expected and will cause distress to the staff who have been involved in caring for the patient. Employers need to ensure that this is recognised and that support models are in place to deal with these situations.
- 6.52 As these staff do not fall within a registration framework requiring them to keep their skills and knowledge updated, the responsibility for this falls on the employer.
- 6.53 **Good PCTs will wish to ensure that the training needs of unregistered staff groups are covered in their local strategies. Employers will wish to ensure that training is provided for these staff.**

### Workforce development in specific settings

- 6.54 Chapter 4 sets out the need to improve the delivery of end of life care in different settings in order for clinical and non-clinical staff to be able to deliver good end of life care. Although some good progress has been made in skilling up staff, nevertheless a great deal more training will be required to ensure that people in all parts of the country benefit.
- 6.55 The main barrier to integrated workforce development across health and social care settings relates to the differences in funding and commissioning for

training. This needs to be addressed if there is to be a shift between end of life care settings.

- 6.56 **Good PCTs, working with local authorities, will wish to give high priority to development of the local workforce through initiatives such as GSF, PPC and LCP and ensure that differing funding processes are not a barrier to integrated workforce developments.**

## e-Learning

- 6.57 Given the size of the workforce and the differing levels of skills, knowledge and attitudes required at different stages of the end of life care pathway, the development of e-learning to support the effective delivery of training is essential. e-Learning for Healthcare (e-LfH) will now give priority to developing e-learning packages for end of life care.
- 6.58 e-LfH is part funded through the Department of Health multiprofessional education and training levy (MPET) and utilises a Learning Management System that can enable up to three million users to be registered. As a priority, the Department of Health has commenced work with e-LfH to develop end of life care e-learning to complement practical learning. Once developed, access will be free to all health and social care staff. The flexibility within the system can provide:
- A lifetime transferable knowledge record;
  - Assessment reports;
  - Learning pathways; and
  - Reduced training costs.

## Taking forward workforce development for end of life care

- 6.59 As outlined earlier in this chapter, many different organisations have complementary roles in the development of the end of life care workforce. Whilst the Department of Health has overall responsibility for much of this, some aspects are the responsibility of independent regulators and professional bodies.

**6.60 To take this forward:**

- **The Department of Health has commissioned a twelve month project with Skills for Care and Skills for Health to develop competences related to all aspects of the delivery of end of life care, due for delivery by June 2009.**
- **The Department of Health will commission from e-Learning for Healthcare a 12 month project to develop e-learning packages related to end of life care.**
- **SHAs will need to develop workforce strategies encompassing all relevant staff groups who contribute to end of life care provision in any setting.**
- **Regulatory and professional bodies and the Royal Colleges are asked to consider reviewing standards and outcome requirements at undergraduate/pre-registration and postgraduate/post-registration levels and review the needs for ongoing continuing professional development.**
- **Medical Schools, other Higher Education Institutions and training providers are asked to consider reviewing the training they provide in relation to end of life care.**
- **Commissioners of services are asked to ensure within their contracts that the skills and competences to deliver quality end of life care are in place.**
- **As a consequence, service providers (statutory, independent and voluntary sector) will be expected to ensure that relevant staff have the skills, competences and attitudes required to provide quality end of life care services, underpinned by access to training programmes and continuing professional development.**



# Part 3:

## Making progress



# Chapter 7: Measurement and research in end of life care

## Introduction

- 7.1 Good information on end of life care is needed by patients, carers, commissioners, clinicians, service providers, researchers, planners and designers and policy makers. Each group will have somewhat different questions to ask and therefore different priorities for information. However, whenever possible data should only be collected once and then made available (in an anonymised form) for multiple purposes.
- 7.2 Ideally information on end of life care should:
- Encompass both health and social care and wider societal issues related to end of life care;
  - Enable patients and carers to make informed choices about their care and the treatments prescribed for them, including the option to say no to treatments they do not wish to take;
  - Enable commissioners to assess the needs of the local population and thus to develop local priorities for action;
  - Enable clinicians to assess the quality of care they are delivering both to individual patients and groups of patients;
  - Facilitate evaluation of each of the broad aims of the strategy (choice, quality, equality and value for money);
  - Facilitate evaluation of progress against each of the pledges to patients and carers;
  - Enable comparisons to be made regarding services and outcomes between different parts of the country (benchmarking and audit);
  - Focus, whenever possible, on the outputs and outcomes of care; and
  - Be a by-product of good care delivery, so that the collection of information is not unnecessarily burdensome.
- 7.3 During the development of this strategy, it has become apparent that currently available information falls far short of this ideal. However, it has also become clear that best use is not being made of existing information.



- 7.4 The particular difficulties relating to the collection of information on outcomes of end of life care should be recognised:
- There may be no clear cut point for an individual patient when end of life care begins;
  - People typically become more frail, less mobile and their level of consciousness decreases as death approaches. Deterioration in these parameters is not in itself a measure of poor care; and
  - As proximity to death approaches, many patients may be unable to participate in questionnaire surveys.
- 7.5 Given this, it may be necessary to seek proxy sources of information on different aspects of care. The use of surveys of bereaved relatives to provide information on the quality of end of life care is discussed later in this chapter.
- 7.6 This chapter sets out:
- A summary of currently available information sources which are available at a national level (Table 5);
  - New information sources which are expected to become available in the near future;
  - A proposed framework for assessment of end of life care (Table 6); and
  - Priorities for development.
- 7.7 At a local level, commissioners and providers have access to more detailed information than is available nationally. Much of this will have been collated through the process to complete the baseline service review, which Primary Care Trusts (PCTs) were asked to undertake in the Operating Framework 2007/08. Local commissioners should, of course, determine what additional information they wish to collect.

### **Current nationally available information**

- 7.8 A significant amount of information on specific aspects of end of life care is already available from a range of different sources (Table 5). However, it is not currently easily accessible to those who may wish to make use of it. In addition, it is difficult, if not impossible, to assess different localities, or organisations, against the key aims and objectives of this strategy.

**Table 5: Current information on end of life care**

Type of information		Source
1	Cause and place of death by age, gender and locality based on death certification	Office for National Statistics (ONS)
2	Information on deaths in hospital (e.g. duration of final admission, specialty, type of admission by age, gender and NHS Trust)	Hospital Episode Statistics (HES)
3	Assessments of need for palliative care in different Strategic Health Authorities (SHAs) and PCTs based on numbers of deaths weighted by deprivation	National Council for Palliative Care – compendium of data for SHAs and PCTs
4	Availability of hospices and specialist palliative care services	Hospice Information Service
5	Uptake of end of life care tools/approaches, for example, Gold Standards Framework (GSF), Preferred Priorities for Care (PPC), Liverpool Care Pathway for the Dying (LCP)	NHS End of Life Care Programme December 2007
6	Examples of innovative practice models	National End of Life Care Programme
7	Establishment of end of life care registers in general practice	Quality and Outcomes Framework (QOF)
8	Uptake of Marie Curie Cancer Care Nursing Services by PCTs	Marie Curie Cancer Care
9	Public awareness and attitudes to death and dying	Several one-off surveys, for example, those conducted by the BBC, Marie Curie Cancer Care and the Cicely Saunders Foundation, National Council for Palliative Care
10	Numbers of deaths reported to the coroner and numbers of post mortems undertaken	Coroners' statistics – Ministry of Justice
11	Complaints about end of life care in the NHS	Healthcare Commission, for example Spotlight on Complaints (2007)
12	Numbers of care homes and care home places	Commission for Social Care Inspection (CSCI)

	Type of information	Source
13	National Survey of Patient Activity for Specialist Palliative Care Services. MDS full report for the year 2005/06	National Council for Palliative Care
14	Funding of specialist palliative care services by PCTs	Department of Health
15	National audit of care of the dying in hospitals (based on the Liverpool Care Pathway)	Royal College of Physicians

### New information sources

- 7.9 Currently available datasets could yield much more valuable information if they were merged. For example, the National Council for Palliative Care is currently undertaking an analysis of deaths in care homes (based on ONS data from death certificates) alongside information on the availability of care home places (based on data from CSCI).
- 7.10 Similarly, the Department of Health has commissioned analyses of combined datasets from HES and ONS. This fusion of data sources provides information on all hospital activity undertaken in the last one, three, six or twelve months of life, using death certification to define the date of death. Until now, analyses of HES data have only been available for patients who have died in hospital.
- 7.11 There is an indicator on end of life care in the National Indicator Set: national indicator 129, which is end of life access to palliative care enabling people to choose to die at home. All local partnerships which have a local area agreement are required to report back to government on progress against all 198 indicators in the national set (even where they do not have a target set against them in the local area agreement). So it will be possible to see how all local partnerships are performing on access to palliative care, and to identify the poor performers.

### Proposed framework for end of life care

- 7.12 Although, ideally, measurement should focus on outcomes, this will take time. In the first instance SHAs, PCTs and Local Authorities (LAs) will wish to consider what measures of structure and process they wish to collect to demonstrate progress on implementation of this strategy. Possible measures are shown in Table 6.

**Table 6: Measurement Framework for End of Life Care**

Care pathway/ setting	Measures of structure	Measures of process	Measures of outcome
Initiation of discussion, assessment, care planning and choice	<ul style="list-style-type: none"> <li>● Training programmes in place for communication skills</li> </ul>	<ul style="list-style-type: none"> <li>● No. of clinicians trained</li> </ul>	<ul style="list-style-type: none"> <li>● Patient/carer experience of communication with clinicians (Views of Informal Carers – Evaluation of Services – VOICES)</li> </ul>
	<ul style="list-style-type: none"> <li>● Training programmes in place for assessment of patients' needs</li> <li>● Agreed care plan format</li> </ul>	<ul style="list-style-type: none"> <li>● No. of assessors trained</li> <li>● No. of patients with care plans and preferred place of care recorded</li> </ul>	<ul style="list-style-type: none"> <li>● % of patients for whom preferred place of care is achieved</li> </ul>
Coordination and use of registers	<ul style="list-style-type: none"> <li>● Establishment of a coordinating centre or equivalent and a locality wide register</li> </ul>	<ul style="list-style-type: none"> <li>● No. of patients on a locality wide register</li> <li>● No. of calls to coordinating centre</li> </ul>	<ul style="list-style-type: none"> <li>● Patient/carer experience of coordinated care (VOICES)</li> </ul>
Home/ community	<ul style="list-style-type: none"> <li>● 24/7 rapid response services or equivalent</li> </ul>	<ul style="list-style-type: none"> <li>● No. of patients using rapid response services</li> </ul>	<ul style="list-style-type: none"> <li>● No. of hospital admissions avoided</li> <li>● No. of deaths in the community</li> <li>● Carer report of experience in the community. (VOICES)</li> </ul>
	<ul style="list-style-type: none"> <li>● No. (%) of general practices using GSF or equivalent</li> </ul>	<ul style="list-style-type: none"> <li>● No. (%) of patients on GP register</li> </ul>	

Care pathway/ setting	Measures of structure	Measures of process	Measures of outcome
Hospital	<ul style="list-style-type: none"> <li>● Senior leadership</li> </ul>	<ul style="list-style-type: none"> <li>● Discussions at Board level</li> </ul>	<ul style="list-style-type: none"> <li>● Carer report of experience of care in hospital (VOICES)</li> </ul>
	<ul style="list-style-type: none"> <li>● No. of clinicians trained in discussing end of life care</li> <li>● Specialist palliative care team</li> </ul>	<ul style="list-style-type: none"> <li>● No. of patients formally assessed by specialist palliative care team</li> </ul>	
	<ul style="list-style-type: none"> <li>● No. of wards trained in LCP or equivalent</li> </ul>	<ul style="list-style-type: none"> <li>● No. of patients dying with LCP or equivalent in place</li> <li>● Participation in LCP audit</li> </ul>	<ul style="list-style-type: none"> <li>● Results of LCP audit</li> </ul>
Care homes	<ul style="list-style-type: none"> <li>● No. of care homes trained in the use of end of life care tools (e.g. GSF, LCP and PPC)</li> </ul>	<ul style="list-style-type: none"> <li>● No. of residents dying with LCP or equivalent in place</li> <li>● No. of patients transferred to hospital in last week of life as an emergency</li> </ul>	<ul style="list-style-type: none"> <li>● Results of LCP audit</li> <li>● Carer experience of care in care homes (VOICES)</li> </ul>
Ambulances	<ul style="list-style-type: none"> <li>● Policies in place regarding Do Not Attempt Resuscitation (DNAR)</li> <li>● Policies regarding urgent transfer out of hospital for dying place</li> </ul>	<ul style="list-style-type: none"> <li>● Measures to be agreed at a local level</li> </ul>	<ul style="list-style-type: none"> <li>● Measures to be agreed at a local level</li> </ul>
Hospices	<ul style="list-style-type: none"> <li>● No. of hospices/ beds</li> <li>● No. of specialist staff</li> </ul>	<ul style="list-style-type: none"> <li>● No. of patients dying in hospices with LCP or equivalent in place</li> </ul>	<ul style="list-style-type: none"> <li>● Carer report of experience of care delivered in hospices (VOICES)</li> </ul>

Care pathway/ setting	Measures of structure	Measures of process	Measures of outcome
Support for carers	<ul style="list-style-type: none"> <li>● Education and training programmes for carers</li> <li>● Respite care facilities</li> </ul>	<ul style="list-style-type: none"> <li>● No. of carers with a care plan</li> </ul>	<ul style="list-style-type: none"> <li>● Carer report of their own experience of support and care (VOICES)</li> </ul>
Bereavement	<ul style="list-style-type: none"> <li>● Education and training for health and social care and widespread provision of appropriate information</li> </ul>	<ul style="list-style-type: none"> <li>● No. of carers supported by care after death section in LCP</li> </ul>	<ul style="list-style-type: none"> <li>● Carers report of their own experience of support and care after bereavement (VOICES)</li> </ul>

## Priorities for development

7.13 **Four key strands of work will be addressed in relation to the development of quality and outcomes measures. These are:**

- **The development of a national tool to measure public awareness and attitudes to death and dying;**
- **The development of quality standards against which PCTs and providers can assess themselves and be assessed by regulators;**
- **Extension of the existing National Care of the Dying Audit based on the LCP; and**
- **Development and implementation of a national programme of surveys of bereaved relatives.**

7.14 Two further strands of work relating to measurement are under consideration. These are:

- Assessment of the number of people dying with a care plan in place. This could potentially be collected from GP registers and/or locality registers; and

- After Death Analysis (ADA) by health and social care professionals of the care given to dying patients. These have been piloted as part of the GSF programme in Walsall PCT and in a further 300 general practices.

### **Box 29: The After Death Analysis Audit Tool**

The ADA is a web-based audit tool that monitors end of life care provision using data drawn from real patient experience. Development work over several years has shown that ADA focuses on key outcomes measures, clarifies areas needing further improvement and is fit for purpose in auditing aspects of end of life care service provision. It is simple and easy to use, enables PCTs and primary care teams to monitor change in practice and supports benchmarking against national trends in end of life care.

ADA originated as part of the GSF Programme in partnership with the University of Birmingham and is supported by the Royal College of General Practitioners as a useful audit tool within primary care.

ADA also:

- Is popular, quick to complete online and user friendly;
- Demonstrates trends based on real life patient case histories;
- Provides a clear objective assessment from which to build further improvements;
- Has been piloted, evaluated and implemented in differing settings (primary care, care homes) and refined from its early stage into a sensitive online tool;
- The online version allows easily visualised feedback through simple bar charts and benchmarking against a unique store of national data;
- Includes a qualitative Significant Event Analysis section which supports reflective practice as a team, encouraging local development based on real patient care;
- Supports PCTs as part of their ongoing reviews, Locally Enhanced Service or other strategic improvement plan;
- In relation to the GSF Primary Care Programme, ADA clarifies levels of adoption of GSF to aid deeper integration into practice, measures change and can benchmark against progress with others;

- Some local audits using ADA have shown an increase in home death rates where GSF was well implemented, a reduction in unplanned admissions, more attaining their preferred place of death and highlighted areas for improvement; and
- In relation to the GSF Care Homes Programme, studies using ADA confirm a significant decrease in hospital crisis admissions and hospital deaths. Use of ADA is now integral to the Gold Standards Framework for Care Homes (GSFCH) programme.

**Contact details:** [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk) or via the GSF helpline on 01922 604666 or [judy.simkins@walsall.nhs.uk](mailto:judy.simkins@walsall.nhs.uk)

## Measurement of public awareness and attitudes

- 7.15 Several large scale surveys have been conducted in recent years to assess public awareness and attitudes to death and dying. These have shown that most people would prefer to die at home, but that discussions about dying and preferences for end of life care are uncommon even between people who are close to each other.
- 7.16 However, each of these surveys has been undertaken once only and the questions used have differed. It is therefore impossible to assess any changes over time.
- 7.17 **To take this forward the Department of Health will commission development of a national assessment tool, which can then be used either at a national level, to assess trends over time, or locally to assess attitudes within specific communities.**

## Development of quality standards

- 7.18 During the development of the SHA visions for end of life care, which formed part of the NHS Next Stage Review led by Lord Darzi, the SHA Pathway Chairs for end of life care unanimously requested that a unified national approach should be taken to develop quality standards for end of life care.
- 7.19 **In response to this, the Department of Health, with input from the SHA Pathway Chairs, has developed draft national standards, on which consultation will commence shortly.**



- 7.20 These draft standards set out what will be needed if high quality care is to be delivered from the perspective of both commissioners and providers (NHS, voluntary and independent). The draft standards are based around the whole systems framework and the care pathway set out in this strategy.
- 7.21 The draft standards are based on the structures and processes of care which are most likely to yield good outcomes for patients who are approaching the end of life and for their families and carers. The standards are accompanied by suggested measures for assessment of compliance.

### National Care of the Dying Audit

- 7.22 A first National Care of the Dying Audit has recently been undertaken by the Marie Curie Cancer Care Palliative Care Institute and the Royal College of Physicians. This has assessed the quality of care given to 2672 patients who died in 94 hospital Trusts in 2006/07. The quality of care for each patient had been documented through use of the LCP. Each NHS Trust provided information on up to 30 patients. Over half of the patients reported did not have cancer.
- 7.23 The audit enables Trusts to benchmark their performance against national findings on a range of domains, including:
- Physical comfort of the patient;
  - Psychosocial and spiritual aspects of care;
  - Communication;
  - Information giving and receiving; and
  - Following appropriate procedures.
- 7.24 **It is strongly recommended that this audit should be extended to involve all acute and community hospitals in England. Over time, the audit process should also be extended to cover patients dying in other settings, including care homes, hospices and at home.**

### Surveys of bereaved relatives

- 7.25 As explained earlier in this chapter, it is difficult if not impossible to collect information on end of life care from representative samples of patients. It is therefore necessary to seek proxy sources of information. Over the past 30 years, extensive experience has been gained first through interviews and more recently with postal questionnaire surveys with bereaved relatives. The

effectiveness and acceptability of administering the VOICES (Views of Informal Carers – Evaluation of Services) questionnaire has been tested in a randomised controlled trial. Research demonstrates that agreement between patients and proxies on many topics is good.

- 7.26 The VOICES questionnaire has recently been extensively revised and tested. Versions have been developed for different conditions, for example stroke and heart failure, and for different settings, for example hospital or community. Further modifications to the VOICES questionnaire are underway to take account of the recommendations set out in this strategy. It will then be possible to assess the perceptions of bereaved relatives/carers concerning:
- Whether the patient was treated with dignity and respect;
  - How well pain and suffering were alleviated;
  - Whether the patient’s needs and preferences were assessed and acted upon;
  - How well care was coordinated across health and social care;
  - The quality of care given in different settings;
  - The quality of care given in the last days of life;
  - The quality of care environments;
  - The quality of care given after death; and
  - The support received by the carer.
- 7.27 **Following appropriate modification and piloting, regular surveys of bereaved relatives will be commissioned by the Department of Health across all PCTs alongside the nationwide patient survey programme.**

### National End of Life Care Intelligence Network

- 7.28 Development of this strategy has highlighted the need to bring all the diverse strands of nationally available information on end of life care together, to transform data into intelligence and to make this information available in forms which are useful for commissioners, service providers and the public.
- 7.29 **To take this forward, the Department of Health will commission the development of an End of Life Care Intelligence Network. This will bring together the various holders of information, Public Health Observatories, national charities, researchers in end of life care**

**and key users of this intelligence, for example PCTs. More detailed proposals will be published later in 2008.**

## Research in end of life care

- 7.30 Development of this strategy has, wherever possible, taken account of the best available research evidence, much of which has been undertaken within the United Kingdom (UK). Examples of such research include:
- Demographic projections of the number of people dying in different age bands in future decades and likely place of death;
  - Assessments of people's preferences and priorities for care as they approach the end of life;
  - Assessment of prognosis for groups of patients with different conditions and analysis of individual patient trajectories;
  - Evaluation of the effectiveness of specialist palliative care services provided in hospices, hospitals and the community;
  - Evaluations of the quality of care provided in care homes and community hospitals;
  - Evaluations of initiatives to improve the quality of end of life care provided in general practice;
  - Evaluations of initiatives to improve care in the last days of life;
  - Evaluations of whole systems approaches to improve care across a community;
  - Assessments of the views of bereaved relatives relating to the quality of care provided to patients in the last year of life; and
  - Assessments of the needs of carers during the patient's illness and into bereavement.
- 7.31 However, development of this strategy has also revealed deficiencies in the current evidence base, which limit the recommendations which can currently be made regarding optimal models of care.
- 7.32 In April 2008, the Department of Health and Marie Curie Cancer Care co-hosted a workshop which brought together around 40 leading researchers and representatives of potential funders of end of life research. The workshop considered the evidence base underpinning each of the key themes of the End

of Life Care Strategy. Opportunities for future research and potential barriers to progress were also considered.

- 7.33 Participants recognised that a considerable body of useful research has been done and is being done. A bibliometric analysis commissioned by the National Cancer Research Institute (NCRI) in 2004 had shown that the output of research from the UK related to supportive and palliative care for cancer was second only to that from the USA. However, on an output per capita basis, the UK ranked below countries such as Sweden, Norway, the Netherlands and Canada.
- 7.34 A review undertaken by the NCRI in 2004 showed that there were around 240 researchers, including PhD students, engaged actively in supportive and palliative care research. These researchers came from diverse professional backgrounds, for example sociology, psychology, general practice, nursing, palliative medicine and public health, and were distributed across more than 40 locations. There was little collaboration with researchers outside the field of cancer.
- 7.35 In response to this, the NCRI partners have invested £5m over five years in two research collaboratives (CECO and COMPASS), which bring together researchers from different disciplines and locations. Subsequently NCRI partners have invested a further £2.25m to enhance supportive and palliative care research, specifically in the field of lung cancer.

### Opportunities for research

- 7.36 Looking forwards, more research is needed on all aspects of end of life care and on care given in different locations. However, particular emphasis now needs to be given to research in areas other than cancer, which have received little attention.
- 7.37 Topics for which significant research opportunities exist include:
- Social attitudes to death, dying and bereavement;
  - Attitudes to end of life issues amongst health and social care professionals;
  - Demographics of dying – especially for causes of death other than cancer;
  - Environments of care;
  - Economics of end of life care;

- Prognostication;
- Advance care planning;
- Communication about end of life issues;
- Changing cultures in health and social care;
- Education and training;
- Understanding current care provision;
- Support for carers (during a patient's illness and after bereavement);
- Effectiveness of different models of bereavement care;
- Spiritual care;
- Care in the last days of life; and
- Effectiveness of different models of bereavement care.

7.38 To maximise the output of useful research in this area, several current limitations and obstacles need to be overcome:

- Palliative care researchers need to be encouraged to look beyond their own field. There may be important issues to learn from mental health, older people and other disciplines;
- There is a need to attract statisticians, epidemiologists, health economists and others into end of life care research;
- New approaches to the evaluation of service developments need to be developed. Currently research is too slow, too expensive and frequently does not come up with results which are useful for policy makers and commissioners; and
- Clinical trials in end of life care could be enhanced by improved access to research nurses, data managers and at least one clinical trials unit.

### **New initiatives on end of life care research**

7.39 Building on the encouraging work being undertaken by the two research collaboratives funded by the NCRI partners, the Department of Health, in collaboration with other statutory and voluntary sector providers, now wishes to see a significant expansion of research in end of life care. Whilst further

research related to cancer patients is still needed, the major emphasis will be on research into other conditions. To take this forward:

- **The National Institute of Health Research (NIHR) Service Delivery and Organisation Programme has identified 'Care provided by generalists at the end of life' as a priority area. The Programme has already commissioned a scoping exercise on research priorities, which is available publicly at the website shown. The Programme is now planning to fund research in these specific priority areas. The intention is to add to the evidence base on a) the commissioning, development, implementation and management of generalist end of life care services in the NHS and wider health and social care system and b) clinical and general management impact upon such solutions. A call for research proposals will be released in September 2008. <http://www.sdo.lshtm.ac.uk/sdo1432006.html>**
- **Research funders are exploring the potential for collectively contributing funding towards a national research initiative on end of life care.**
- **There is a need to develop methods for the evaluation of new service models in end of life care – for example, methods that can be applied routinely to evaluate the many natural experiments that arise in the NHS from service re-design. The Medical Research Council is considering the most appropriate way of taking this area forward through its Methodology Research Programme.**



# Chapter 8: Making change happen

## Introduction

- 8.1 Action will be needed at many different levels to turn the vision set out in this strategy into reality, thereby improving the care delivered to hundreds of thousands of patients and families each year.
- 8.2 Publication of an End of Life Care Strategy should in itself start to raise the profile of end of life care in this country. But this alone will not be enough. Sustained leadership and drive will be needed both nationally and locally to ensure that appropriate actions are taken at each step in the end of life care pathway described in chapter 3 and across all the settings described in chapter 4.
- 8.3 This chapter sets out:
- Information on current and future funding for end of life care;
  - The responsibilities of individual organisations at various levels for delivering change;
  - The levers available through the healthcare reform agenda to help drive change at each level;
  - The national support that will be available to help local commissioners and providers implement change; and
  - The need to monitor progress at all stages.
- 8.4 Strategic Health Authorities (SHAs), Primary Care Trusts (PCTs), Local Authorities (LAs) and provider organisations will wish to consider the draft quality standards described in chapter 7, alongside the actions recommended in this chapter. It is hoped that the draft quality standards will help commissioners and service providers to assess their own progress towards implementation of this strategy. The draft standards will also hopefully be useful to SHAs in their performance management of PCTs and to PCTs in their contracting and performance management of service providers.



## Funding for end of life care

8.5 It is difficult, if not impossible, to calculate the cost of end of life care in this country. This is partly because of the difficulty in defining exactly when end of life care starts. However, the key elements of expenditure can be identified. These are:

- Hospital admissions: the total cost of non-elective final finished consultant episodes ending in death amounts to around £750m pa. Some of these will, of course, have been unexpected deaths. Other patients will have been recognised to be dying during an admission and will have been transferred elsewhere to die. Their costs are not shown in the £750m;
- Hospices and specialist palliative care services: these are estimated to cost around £450m pa of which over £200m is borne by the voluntary sector. NHS funding for specialist palliative care services varies widely between PCTs;
- Community nursing services: the Audit Commission estimated in 1999 that end of life care took up 40% of district nurses' time, though it only accounted for 8% of their caseload. The cost of district and community nursing in 2005/06 was around £1bn; and
- Care homes: a currently unquantified cost, some of which is met from NHS Continuing Care Funds and a significant proportion from the private purse.

8.6 Across health and social care the overall cost of end of life care is large (measured in billions of pounds) and there is widespread agreement that these resources are not all being used as well as they might be. In addition, there are costs met by other government departments such as the Attendance Allowance and Disability Living Allowance and, of course, there are costs to unpaid carers.

8.7 Many of the improvements envisioned by the strategy can be achieved by better use of existing health and social care resources. It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay. Further work on the cost impact of new end of life care service models developed through the Marie Curie Cancer Care Delivering Choice Programme are encouraging, showing a reduction in hospital admissions and increase in home deaths, whilst overall costs remain stable.

## Funding of specialist palliative care services

8.8 A survey of specialist palliative care funding was undertaken by the National Council for Palliative Care, on behalf of the Department of Health (DH), in 2000. This showed that the total expenditure on specialist palliative care in England was £300m.

**Table 7**

	Expenditure (£m)		
	Voluntary	NHS	Total
Adult voluntary hospices	150	65	215
NHS bedded specialist palliative care units	–	34	34
Community specialist palliative care teams	20	17	37
Hospital specialist palliative care teams	–	14	14
Total	170	130	300

*Source: National Council for Hospice and Specialist Palliative Care Services, 2000*

8.9 Since then, there has been growth in expenditure, both from the voluntary sector and the NHS. Expenditure by the NHS was boosted by an extra £50m pa from 2003/04 as part of the delivery of the NHS Cancer Plan (2000).

8.10 During the development of this strategy, we conducted a survey of PCTs to obtain information on their expenditure on hospices and specialist palliative care services in 2006/07. This showed:

- A total NHS expenditure of around £250m;
- An average spend of around £5 per head of population, and an average spend of around £500 per death from any cause; and
- Expenditure per death at PCT level varied considerably from around £150 per death to around £1650 per death.

## Future spending on end of life care

- 8.11 In its election manifesto in 2005, the government committed to double the investment in palliative care. Given the lack of data on the cost of end of life care services (as identified above), a decision was taken to interpret the manifesto commitment to mean doubling funding for specialist palliative care services. Taking the figure for NHS expenditure on specialist palliative care in 2000 (£130m, see Table 7) and the additional £50m from 2003/4, the level of funding needed to double the investment was identified as £180m.
- 8.12 The government is committed to spend an additional £88m on end of life care in 2009/10. This figure will rise to £198m in 2010/11 (see Table 8), thereby meeting the manifesto commitment. The Impact Assessment, which is published alongside this strategy sets out estimates of the additional expenditure that will be needed to deliver the strategy.

**Table 8**

Projected rise in expenditure on end of life care			
Year	Revenue	Capital	Total
2009/10	£80m	£8m	£88m
2010/11	£150m	£48m	£198m

- 8.13 The key areas in which investment is needed are:
- Rapid response services available 24/7;
  - Enhanced specialist palliative care services for people with conditions other than cancer, including additional services in care homes;
  - Workforce development;
  - Coordination centres;
  - Additional transport; and
  - Improved measurement/monitoring of end of life care.
- 8.14 Most of the additional funding will go into PCT baselines, in line with policy related to the devolution of responsibility and resources to the front line. PCTs will be expected to develop local plans to show how they will deliver the commitments in the strategy.

- 8.15 **The government is committed to new investment in end of life care. In the Operating Finance Guidance for 2009/10, which will be either referred to or included in the Operating Framework for 2009/10, we will inform PCTs that we will expect this investment to be properly monitored, through the resources and applications planning form.**
- 8.16 Funding for workforce development will go to SHAs as the commissioners of education and training.
- 8.17 A small proportion of the funding will be held centrally. This will support the delivery of a number of areas of national work to underpin the strategy, including:
- Providing support to the National Council for Palliative Care to establish a national coalition to promote awareness of end of life issues;
  - Maintaining a small national team to disseminate good practice;
  - Developing a national Intelligence Network for end of life care;
  - Developing and implementing a national survey programme to elicit the views of bereaved relatives;
  - Providing support for the development and roll-out of national audits of end of life care services;
  - Piloting the implementation of end of life care registers;
  - Providing support for the development of a competence framework for end of life care to support workforce development initiatives;
  - Establishing a group to provide advice and oversight on the implementation of the strategy;
  - Consulting on a set of quality standards for end of life care; and
  - Enhancing research into end of life care.

### Primary Care Trusts and Local Authorities

- 8.18 **PCTs and LAs are responsible for commissioning end of life care services and stronger commissioning will underpin many of the improvements set out in this strategy.** This will require PCTs and LAs to work together to achieve improved health and wellbeing outcomes for their populations, and should be based on a sound Joint Strategic Needs Assessment (JSNA) that all PCTs and LAs are required to produce from April 2008. World class commissioning is now being introduced across the NHS.

This will bring a new, professional rigour to commissioning. The objective is to improve the quality of life for individuals and to reduce health inequalities to 'add life to years and years to life'. A key aspect of world class commissioning will be excellent engagement with the local population and clinicians. PCTs will undertake detailed needs assessments of the local population's health and will need to engage with the public to determine health priorities. This will include understanding the wishes of the local population in relation to end of life care.

- 8.19 The NHS Operating Framework for 2007/08 asked PCTs, in conjunction/ partnership with LAs, to undertake a local end of life service baseline review in preparation for the publication of the End of Life Care Strategy. Guidance on the areas PCTs and LAs might want to include in the review was set out in *Operating Framework 2007/08: PCT baseline review of services for end of life care* (April 2007, Gateway reference 8116). This was further strengthened in the Operating Framework for 2008/09, which specifically referred to improving access to high quality, coordinated services, close to home, as a key theme emerging from the development of the strategy. The operating framework suggested that central to the delivery of this change would be the development of rapid response services and coordination centres. The work on baseline reviews should now have been completed. This should be one of the information feeds into the JSNA, which in turn will inform the priorities for inclusion in the PCT prospectus.
- 8.20 LAs have a role to support PCTs in delivering end of life care. The appropriate level of involvement will be different in each place. A small number of areas have selected end of life care (National Indicator 129) as a priority in their local area agreement, the main service planning and delivery agreement for the local area. This means that those areas will have a target owned jointly by the PCT, the LA and other local partners. Areas which have not prioritised indicator 129 will still be required to report on progress against this indicator. They will also have the previously mentioned obligation to collaborate with PCTs on the JSNA. Good LAs will want to make sure that their services are as well coordinated as possible with PCTs and other providers, in order to offer the best possible service to the communities they serve.

8.21 **In line with the NHS Next Stage Review (NSR), PCTs, working with LAs, should develop local strategic plans based on the framework outlined in this strategy and incorporating a care pathway approach.** To do this effectively they will need to ensure that they:

- Assess the end of life care needs of their populations, paying particular attention to the need to reduce inequalities. A local Equality Impact Assessment will help to do this and will be a key tool to support the development of a Joint Strategic Needs Assessment (JSNA), which is capable of being responsive to all segments of the community;
- Engage a wide range of provider organisations, including the voluntary sector and patient and carer representatives to help formulate a plan for integrated service delivery;
- Determine how best to commission services in line with their local strategy, which provides choice, quality, equality and value for money;
- Procure and contract for services effectively; and
- Monitor progress.

**The key conclusions and proposals from these plans should be reflected in PCT Prospectuses and their medium term plans to be reviewed every three years.**

8.22 The National Council for Palliative Care published a 'Population Based Needs Assessment for End of Life Care' in September 2006. PCTs and LAs may find it a useful starting point for their local needs assessment. It provides a compendium of data for SHAs and PCTs, taking account of the numbers of deaths per 100,000 population and the level of deprivation in each PCT. The National Council document is being updated to refine the conditions it covers. The latest version will be available from [www.ncpc.org.uk](http://www.ncpc.org.uk)

8.23 The new requirement to produce a JSNA only began in April 2008, but in future, local strategic plans should be guided by the results of the JSNAs. JSNAs will be the means by which PCTs and LAs will identify the future health, care and wellbeing needs of local populations and will help to set the strategic direction of service delivery to meet those needs.

8.24 The JSNA should be taken into account by the LA in its preparation of the Sustainable Community Strategy, the overarching strategy for the area. The issues identified in the JSNA will have a bearing on the priorities and targets in the Local Area Agreement.

- 8.25 **To develop an effective local strategy, PCTs and LAs will need to engage with provider organisations (including voluntary sector providers) at a senior level.** They may want to establish a partnership board, network or similar 'alliance' to take forward strategic service planning, and/or share their outline strategic plans with their provider forum. Decisions on how this should be done locally will remain with the local PCT/LA. However, they will want to ensure they have senior level engagement with community service providers, acute hospitals, the care home sector, hospices, other voluntary and independent sector providers, ambulance services, out of hours service providers and any others who have a role in end of life service provision in their area. They should also ensure that due consideration is given to the legal duties that apply under equality legislation.
- 8.26 When commissioning services from care homes, PCTs and LAs will wish to jointly ensure that the care home has appropriate mechanisms and staff in place to identify, assess and plan care for residents who are approaching the end of life. PCTs will also wish to ensure that medical and nursing services required by people at the end of life are available to residents of care homes, sheltered and extra care housing and that the environment is suitable for such services.
- 8.27 **PCTs and LAs are reminded of the need to comply with the Department of Health's *Principles and Rules for Co-operation and Competition* published in December 2007, which includes a requirement to adhere to the Compact on Relations between Government and the Voluntary and Community Sector in England.** Contracting arrangements should provide a fair playing field for all providers, including hospices and other third sector organisations. Transparent commissioning should facilitate more funding stability, including the provision of longer term contracts in the right circumstances, a common understanding of cost structures and fair pricing and the need to assign risk fairly and proportionately between commissioner and provider.
- 8.28 With respect to the Compact, PCTs may wish to be aware of a research project being undertaken by the Commission for the Compact and Help the Hospices. The research examines, through the medium of ten case studies, how well the Compact is currently implemented in relationships between PCTs and ten hospices in England. The research provides evidence as to whether the Compact has been effectively embedded in PCT and hospice arrangements. The case studies offer examples of both good practice and practices where significant challenges remain. These will be useful to all stakeholders involved in commissioning and delivering end of life care services

from the third sector. The report *Learning for End of Life Care: positive engagement, future practice* is due for publication later in 2008.

- 8.29 As stated, stronger commissioning will need to underpin many of the improvements set out in this strategy. To address this, draft quality standards have been developed in response to and in collaboration with SHA clinical pathway chairs for end of life care.
- 8.30 PCTs and LAs, in conjunction with SHAs, will need to decide whether their strategy covers just their own population, or whether to work in partnership with adjacent PCTs and LAs to produce a single local strategy.
- 8.31 PCTs and LAs may also need to consider issues of geographical equity of funding within the boundaries of the PCT and LA.

### Strategic Health Authorities

- 8.32 **Working in consultation with PCTs, LAs, Regional Offices and Directors of Adult Social Services, SHAs will need to determine whether strategies should be developed at single PCT level or by consortia of PCTs. Either way, they will want to ensure that local strategies cover the whole of their population.**

#### **Box 30: Cross-SHA approach to commissioning end of life care services: London**

Whilst recognising that London is different from many other parts of the country, *Healthcare for London: a framework for action* sets out one possible approach to organising the delivery of end of life care services.

In December 2006, NHS London asked Professor (now Lord) Ara Darzi to carry out a review of London's healthcare and to make recommendations. One of the clinical expert working groups reporting to Professor Darzi looked specifically at end of life care.



Central to the recommendations of the end of life clinical working group was the need for strong specialist commissioning of end of life care services. The group believed that there were good arguments for locating the commissioning of adult end of life care at the sector level (areas co-terminus with the previous London SHAs), each serving populations of 1.5–2m. They felt that commissioning at this level would enable meaningful community engagement and a degree of diversity and may also enable patients to exercise choice within their area between two or more End of Life Service Providers (ELSPs). The group felt that the Practice Based Commissioning, or PCT level, was too small for the right skills and capabilities to reasonably develop and would lead to unnecessary duplication and variability in such complex and specialist commissioning.

The group also felt that:

- Commissioning of care should be based on a detailed specification and should enable a variety of managed networks across providers to bid for the contract to provide services;
- Those bidding for the contract should offer an integrated and comprehensive service that included community nursing, GP organisations, specialist palliative care teams, LAs, the voluntary sector and acute care providers;
- Services should be coordinated as part of a contract with PCTs to be delivered across the public, private and voluntary sectors;
- PCTs and LAs should be challenged to find a way to come together in this commissioning process to commission appropriate integrated specialist services;
- The process should be based on a care pathway for end of life patients and delivered through a managed network of providers; and
- PCTs should identify a clear financial envelope for this purpose and clear performance metrics should be developed to monitor the contract and drive up quality.

8.33 SHAs will wish to satisfy themselves that an inclusive approach has been taken in the development of local strategies and, for example, that strategies:

- Cover each aspect of the strategy and each step in the end of life care pathway;

- Reflect the identified needs of the population and the local decisions about priorities based on the identified needs;
- Will enable more patients to live and die in the place of their choice;
- Will support a shift in the balance of care from the acute sector to the community, with 24-hour medical and nursing services available to patients in all locations;
- Include effective arrangements to coordinate individual patient care;
- Take into account training and other workforce development requirements;
- Include monitoring processes;
- Take account of the environments in which end of life care is delivered; and
- Ensure there is sufficient diversity of provision and that the NHS is making appropriate and effective use of all the capacity and resources available in the wider system, including the independent and voluntary sector.

8.34 **Workforce development will be one of the major cost drivers for improving end of life care. SHAs will need to take into account additional workforce development needs arising from their local end of life care strategies in devising and monitoring their training and development plans.**

## Primary care

- 8.35 **Primary care teams will wish to ensure that they can identify, assess and plan care for people approaching the end of life.** They will also wish to document decisions taken with the person and have mechanisms to ensure good communication both within the primary care team and with other care providers, for example, out of hours services. Where they do not already exist, processes need to be put in place to ensure that patients approaching the end of life are reviewed regularly.
- 8.36 Primary care teams will wish to ensure that relevant staff have the necessary competences to communicate effectively and assess the needs of people approaching the end of life and their carers.

## Hospitals

8.37 **As set out in chapter 4, hospitals will continue to be major providers of end of life care for the foreseeable future. Boards of provider organisations should therefore take responsibility for ensuring they provide high quality end of life care.** In particular, they should ensure that they have in place:

- A plan for end of life care which is congruent with the strategic plan developed by the PCT for the locality;
- An appropriately constituted specialist palliative care team;
- Processes in place to identify patients approaching the end of life;
- Processes for assessment and care planning;
- Accommodation that is available and suitable for end of life care;
- Timely and coordinated discharge;
- Effective links and information exchange with palliative care community based services;
- Frameworks to ensure delivery of high quality care in the dying phase and after death;
- Appropriate support for families and carers;
- Monitoring and audit processes; and that
- Relevant staff have the necessary competences to initiate discussions regarding end of life and to meet physical, psychological, social and spiritual care needs.

8.38 Service providers will have their own assurance mechanisms but may want to consider, for example, reviewing quality of end of life care provision at board level at least once a year.

## Care homes

8.39 **Care homes will wish to ensure they have developed a plan for end of life care which is congruent with the strategic plan developed by the PCT and LA for the locality.** They should ensure that they have appropriate mechanisms and staff in place to identify, assess and plan care for residents who are approaching the end of life. They should work with PCTs to ensure that medical and nursing services, including associated facilities, required by people at the end of life are available to their residents.

- 8.40 Those responsible for providing services in care homes, and sheltered and extra care housing, are strongly encouraged to engage in programmes to enhance the quality of care they provide, and PCTs and LAs are strongly encouraged to support care homes in this. Further details are given in chapter 4.

## Hospices

- 8.41 **Hospices, whether managed by the voluntary sector or the NHS, will wish to work with PCTs to ensure that their role as providers of specialist care, advice and education within the local health economy is appropriately defined.**
- 8.42 Hospices and other voluntary sector organisations will wish to consider what new services they might wish to provide to contribute to the vision outlined in this strategy. Any new services which are agreed as part of a local strategy should be fully funded from statutory sources. Chapter 5 within *Improving financial relationships with the third sector: guidance to funders and purchasers (2007)* sets out the rationale for 'full cost recovery' for third sector providers and how it is legitimate for providers to include the relevant portion of overheads in cost estimates for delivering a service. Hospices should especially consider how to ensure equity of access to their services for the whole of the population of the catchment area that they serve, including people from culturally diverse backgrounds and/or with conditions other than cancer.

## Royal Colleges and professional societies

- 8.43 Royal Colleges and professional societies will wish to raise the profile of end of life care within their membership. They may also wish to strive to develop a consensus amongst clinicians on the importance of initiating discussions about end of life issues and on appropriate points in the trajectory of different diseases for such discussions to take place.
- 8.44 **Royal Colleges and professional societies will wish to ensure that their members have the necessary knowledge, skills and attitudes to be able to deliver high quality care.** End of life care needs to be appropriately covered in postgraduate curricula and it is strongly recommended that this is subject to assessment. Consultants should be encouraged to participate in continuing professional development related to end of life care.

## Regulators of health and social care services

8.45 The Commission for Social Care Inspection and the Healthcare Commission have responsibilities for regulating and assessing health and adult social care organisations. It is intended that these bodies, and the Mental Health Act Commission, will be replaced by a new regulator – the Care Quality Commission. In establishing the new joint health and social care regulator, the Department of Health will work to ensure that registration requirements and systems for licensing providers support the development of service models for end of life care.

## National leadership and oversight of implementation

8.46 Although responsibility for implementation of this strategy resides predominantly with SHAs, PCTs, LAs and provider organisations, national leadership and oversight will also be important. This will help to ensure that progress is made as rapidly as possible in all parts of the country.

8.47 **Building on the work of the current NHS End of Life Care Programme, a small national multiprofessional support team will be maintained to support the work being undertaken at SHA and PCT levels. The main function of this team will be to share good practice emanating from different parts of the country.**

8.48 The national End of Life Care Programme will continue to have a valuable role in sharing good practice across all aspects of the strategy, including:

- Local profile raising regarding end of life care issues;
- Strategic commissioning by PCTs and LAs;
- Each step in the end of life care pathway;
- Workforce development; and
- Environments of care.

8.49 The national End of Life Care Programme will work closely with the end of life care Intelligence Network (described in chapter 7) to ensure that information on services and outcomes is used to drive up the quality of care across the country.

8.50 Development of this strategy has been led by Professor Mike Richards who chaired the Advisory Board. Ongoing national leadership will be essential to oversee implementation of the strategy, to take forward work on quality

standards and to engage with all key stakeholders to ensure that progress is maintained. Professor Richards has agreed to continue providing this leadership.

- 8.51 The government is committed to tracking progress on end of life care to ensure that the aims of this strategy are achieved. Professor Mike Richards will deliver annual reports on progress to Ministers. The end of life care Intelligence Network will provide valuable input to these reports. An advisory board of stakeholders, facilitated by the Department of Health, will also be convened to provide input into each annual report.



# Annex





# Annex

## **Documents published alongside the End of Life Care Strategy**

Executive Summary of the End of Life Care Strategy

What the End of Life Care Strategy means for patients and carers

Equality Impact Assessment

Impact Assessment

Survey of expenditure by PCTs on hospice/specialist palliative care services for 2006/07

End of Life Care Strategy: Bibliography

Advisory Board and Working Group membership



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